

**B COMMISSIONED STUDY ON THE BENEFITS  
AND DIFFICULTIES OF INTRODUCING A  
NATIONAL APPROACH TO ELECTRONIC  
HEALTH RECORDS IN AUSTRALIA**



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# The benefits and difficulties of introducing a national approach to electronic health records in Australia

**Report to the Electronic Health Records Taskforce**



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**Commonwealth Department of Health and Aged Care**

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This report forms part of the work of the National Electronic Health Records Taskforce, established as a response to the *Health Online* policy document.

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## Part 1 Executive Summary



This summary provides an overview of the key benefits and difficulties of introducing a national approach to electronic health records in Australia and discusses what needs to be done to ensure that the benefits are realised and the difficulties overcome.

The electronic health record (EHR) is a necessary tool for providing person-centred and continuing health care safely and efficiently in the modern information environment. It is not a stand-alone system in a doctor's surgery or in hospital outpatients; rather, it is a longitudinal collection of information about a person's health that is stored at the point of care, and which may be moved or accessed with the individual's specific consent by health professionals at other sites involved in providing care. Appropriate and accountable access to this information (through necessary standardisation) is the main technological challenge to implementation of the EHR envisaged in the *Health Online* policy document. Other challenges to the implementation of the EHR include organisational and cultural barriers, legal issues, user acceptance issues, market issues, as well as the leadership and vision of decision makers. Finally the ultimate challenge is to establish and develop electronic health records in a framework that ensures consumer confidence and trust while encouraging greater consumer participation in and responsibility for health.

There are substantial benefits to consumers and health professionals, as well as to managers, researchers and policy makers in implementing EHR systems. There are particular advantages if this can be done within a national framework which supports and actively promotes use and communication of the EHR by consumers and health care providers. The barriers can be overcome if sufficient attention is paid to the key issues described in this report - in particular, the privacy of personal health information and the acceptance of EHR systems by the health professionals.

There is some evidence that the use of an EHR leads to improved health outcomes. If implemented appropriately, it can enable the consumer to take a more active role and make more informed decisions about their health. The EHR can aid efforts to improve the health of underserved populations while increasing the accountability of health care professionals. There is no doubt that EHR systems can provide rapid access to health records for health providers and improve the assistance available through personalised decision support and speedy access to high quality information. The quality and safety of data and security and efficiency of storage can also be improved through the introduction of an EHR. From a management perspective the EHR can substantially improve the quality and efficiency of health services, while enable reporting of various attributes of the health care provided such as work patterns and trends. Finally, the EHR can be used for population and medical research as well as the systematic assessment of the quality of care and outcomes across the nation.

There are important difficulties to consider - particularly the legal issues surrounding privacy and security of data. The EHR needs to be a concise concept so that consumers can be sure where their record is, what is in it and who has had access to it. The balance between ease of (appropriate) access and security is difficult to manage. Further, some

groups in the population may be left out of the new health paradigm due to distance, inappropriate demands or lack of resources. There are many technical difficulties to overcome in fields such as data entry, EHR transfer and person identification. Health care professionals are the key users and must find the system acceptable - achieving this is not straightforward and will certainly require training and support. The choices we face are particularly difficult with the rapid changes taking place in the health information environment and the sometimes divergent international developments in technology and information handling.

The experiences of Canada, New Zealand and the United Kingdom can prepare us for the way ahead, but the ground remains largely uncharted. These governments have made choices and enacted legislation. They have supported their EHR developments by setting up organisations to administer components such as centralised databases, national personal identification numbers and even clinical guidance. We must continue to cooperate closely with international efforts and undertake complementary research and development.

Indeed, as is demonstrated by the review of international and Australian experiences provided in this report, both the costs and risks of developing EHR systems will be greater if we do not take the opportunity to work within a nationally focused set of technical and legislative guidelines.

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## **1.1 ASPECTS OF A NATIONAL APPROACH REQUIRED TO ENSURE BENEFIT**

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### ***Benefit for Consumers***

- The new paradigm demands an explicit legal framework for the EHR including
  - a requirement for each site to publish clear information policies and procedures to ensure appropriate work practices,
  - a national EHR security and privacy framework with uniform legislation, and
  - a national approach to training health professions who access EHRs in the understanding of the duty of confidentiality and the legal sanctions for not observing it.
- The needs of consumers and health professionals will have to be reconciled through involvement of consumers in EHR system design so that the aims of both parties can be achieved.
- Data entry tools for consumers and a consumer 'view' of clinical (coded) information need to be developed and the EHR architecture needs to evolve to support this.
- A suitable registration and certification scheme needs to be implemented for health professionals who make themselves available on line - controls may be required.
- Monitoring of EHR services needs to be established in various contexts to ensure equity of access for all consumers.

### ***Benefit for health professionals***

- Health professionals must accept the EHR systems. To do this they
  - must be involved in and feel committed to the introduction of EHR systems, and
  - should lead the introduction of the system.
- Introducing EHR systems must take place in a transparent and evolutionary framework with best practice guidelines and careful change management.

- EHR systems must support clinical decision making and information access at the point of care through
  - a standard terminology and medication identifiers,
  - standard messaging, and
  - a fast communications network available to the clinician at the point of care.
- EHR systems should support EHR transfer, access to audit tools, and future proofing of EHRs through a standard health record architecture
- Consumer understanding of the need for student health professionals to undertake supervised access to EHRs must be assured

***Benefit for managers***

- A legal framework and best practice guidelines need to be established for
  - security of health data,
  - managing the introduction the EHR,
  - the balance of access and security appropriate in different settings,
  - system performance and useability,
  - collecting management data as a by-product of recording care.
- The introduction of a personal identification number (PIN) needs to be carefully considered to support management of health services.
- The vision of the health system of the future needs to have a 'step wise' implementation that is coherent and safe and reasonably inclusive.
- Health care professionals and consumers need to be aware that the importance of the EHR will often extend beyond the immediate consultation and for that reason will need to be structured and carefully maintained.
- Transparent methods of requesting and recording of consent for use of personal health data for management purposes should be incorporated into the EHR development.
- A mechanism to bring about standardisation of EHR systems needs to be instituted, providing added resources for those who fully implement standards, some of which must be passed on to system developers.

***Benefit for software developers***

- A balanced approach to the introduction of standards
  - which are easy to implement,
  - have a limited number of specific implementations (i.e. a generic solution),
  - are supported by rapid expert decision making,
  - are internationally compatible where possible, and
  - are kept up to date.
- A commitment to ensure benefit from the introduction of standards through
  - seeking acceptance by the appropriate industry body that the standard is suitable,
  - proposing reasonable time lines for implementation of standards, and
  - ensuring financial reward or at least no financial disincentive for implementing these standards.

***Benefit to society***

- The roles of the EHR are determined within the health model operating in that State or Territory.
- Open standards are required to underpin the EHR which prevent 'lock in' to proprietary solutions and maintain interoperability and communication.
- Introduction of a national health person identification number (PINs) to allow record linkage and thus quality information for research and policy development.
- Establishment of an agency to monitor and advocate for implementation of the EHR, particularly for consumers and health professionals.
- Explicit accreditation of EHR systems through a transparent process and undertaken by a body with a consumer focus and mandate.
- Nominated national organisations to undertake and advocate for the ongoing development of the 'building blocks' of the EHR and guide its use nationally.

***Priority areas***

The priority areas<sup>1</sup> requiring a national approach are:

1. A culture of trust and teamwork amongst consumers and health professionals that enables shared care and cooperation.
2. Technical standards:
  - Standardised terminology;
  - Standards for communication of the record, parts of the record or messages;
  - A record architecture standard;
  - Standardisation of security such as signature, non-repudiation, authentication, and encryption;
3. A national legal framework that ensures confidentiality of personal health information, accountability of clinicians through digital signatures and authentication systems, and permanence, completeness and accuracy of data.
4. An industrial and market situation that encourages good quality systems to flourish. The systems need to be provided with ongoing support and training of users and support use of the information for improved health care.



## Part 2 Introduction



*Health Online*<sup>2</sup>, the Health Information Action Plan for Australia acknowledges that the global information economy is changing the way we live and work. Computers have the ability to store, read and process very large amounts of information and to do so very quickly. These attributes have made them increasingly attractive to health care providers who are sinking under a growing 'mass' of records and other information. Electronic health records (EHRs), and the consequent promise of a paperless (or less paper) environment, have become the principal objective of those utilising information technology to improve health care systems around the globe. However, the complexity of health information and the lack of a common approach have continued to confound these efforts.

Consumers, health care professionals and managers need to be sure that the transition to widespread use of EHRs is in their interests. In particular, consumers need to be sure that their health care, and ultimately their health, will benefit and that the privacy of their personal health information is guaranteed.

This report investigates the benefits and difficulties, proven and theoretical, that arise from the implementation of EHRs and considers what might be achieved from taking a national approach to this process.

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### 2.1 EXPLANATION OF APPROACH

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From a strategic point of view, the benefits and difficulties of EHRs and of introducing a national approach, must be considered together. As will become clear, however, assessing both costs and benefits, separately or together, is problematic<sup>109</sup>. This report draws largely on evidence in the literature, on online information from information technology and health organisations directly involved in developing aspects of the EHR, and on considered expert opinion. Thus, the report incorporates both theoretical and practical knowledge of, and experience with, the development and implementation of EHRs. Although financial issues are addressed in the report, there have been few studies evaluating EHR systems from an economic perspective. The use of EHR systems in health care will probably require the development of new methodologies in economic evaluation.

#### 2.1.1 THE PURPOSE OF THIS REPORT

The purpose of this report is to enable health consumers, health professionals, organisations interested in policy matters, Commonwealth, State and Territory Governments and the information industry to have a clear understanding of the issues involved in the development of electronic health records in Australia.

#### 2.1.2 BENEFIT AND DIFFICULTY

Both benefit and difficulty can be expressed in technical and human terms - one is often the corollary of the other. This report intentionally expresses benefit primarily in human terms - improvements in cost, functionality or efficiency for the people concerned with health care. Difficulties are expressed primarily in technical and ethical terms - that is to say, the report identifies the barriers to achieving benefit.

### **2.1.3 METHODS**

An extensive literature review was undertaken during the preparation of this report. A search of the Medline database (using GratefulMed) with the thesaurus term “Computerised Medical Records” was carried out for the period 1990-1999. Only papers where “Computerised Medical Records” was the primary focus of the paper were selected. This yielded approximately 1000 entries. These abstracts or titles were reviewed by a consultant and two research assistants and any articles describing benefits and difficulties of computerised medical records were chosen. This left approximately 300 references and the reference lists of these papers were also searched for further relevant articles. An internet search was carried out and the websites of key information technology and health care institutions were examined for relevant information. Major books on the subject, conference proceedings from AMIA (1997, 1998, 1999), the Centre for Advancement of Electronic Health Records (Towards and Electronic Health Record Europe 99) and the Australian HIC (1998 and 1999) were scanned. A total of 643 articles, conference proceedings, books or chapters and reports were accessed in preparing this report and more than 300 have been directly cited. Comments were sought from the Electronics Health Records Taskforce on drafts of the report and responses incorporated. The report also benefits from the authors’ practical experience in the area of health informatics over many years.

## Part 3 Background



The setting for the development of electronic health records is an important consideration when adopting a national approach. This part of the report defines the EHR and its purposes, states relevant principles from the *Health Online*<sup>2</sup> report and describes the characteristics of the current health care environment.

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### 3.1 SCOPE

When addressing the issue of electronic health records (EHR) it is important that there is no ambiguity as to what is meant by the term. This section considers what constitutes an EHR, the boundary of the EHR and the purposes of an EHR.

#### 3.1.1 WHAT IS AN EHR?

The term Electronic Health Record (EHR) is widely used to refer to electronic, or computerised records in health care, although the terms ‘Computerised Patient Record’ (CPR), ‘Computer-Based Patient Record’ (CPR), ‘Electronic Medical Record’ (EMR), ‘Computerised Medical Record’ (CMR) or ‘Electronic Health Care Record’ (EHCR) are similarly applied and there is no consistent distinction between the terms.

The United States uses the term computer-based patient record or CPR and the Institute of Medicine<sup>3: p55</sup> defines it as:

*an electronic patient record that resides in a system specifically designed to support users through availability of complete and accurate data, practitioner reminders and alerts, clinical decision support systems, links to bodies of medical knowledge, and other aids.*

The United Kingdom has accepted two kinds of electronic records in health care – the electronic patient record (EPR) and the electronic health record (EHR)<sup>4</sup>. These concepts are described below.

*Electronic Patient Record (EPR) describes the record of the periodic care provided mainly by one institution. Typically this will relate to the health care provided to a patient by an acute hospital. EPRs may also be held by other health care providers, for example, specialist units or mental health NHS Trusts.*

Thus, EPRs are considered proprietary and it is usual for EPRs not to be able to be transferred even to another site using the same EPR system.

*Electronic Health Record (EHR) is used to describe the concept of a longitudinal record of patient’s health and health care – from cradle to grave. It combines both the information about patient contacts with primary health care as well as subsets of informa-*

*tion associated with the outcomes of periodic care held in the EPRs.*

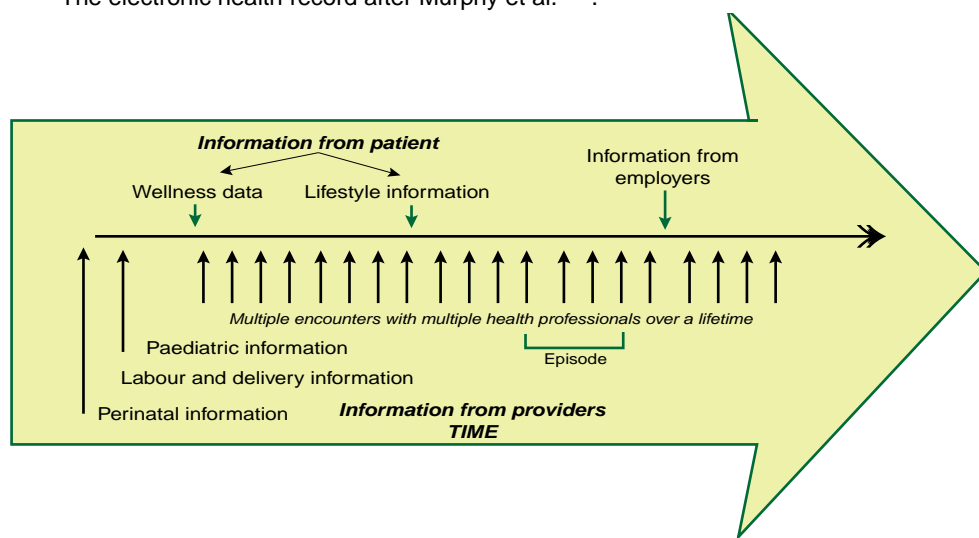
Electronic health records are not available as yet in the UK but the *Information for Health* policy statement and the ScopeEPR project both support “developing and implementing a first generation of person-based Electronic Health Records, providing the basis of lifelong core clinical information with electronic transfer of patient records between GPs”.

For the purposes of this report, the division between EPRs and EHRs is not considered to be particularly useful. Thus, this report will consider the Electronic Health Record to be:

**an electronic longitudinal collection of personal health information, usually based on the individual or family, entered or accepted by health care professionals which can be distributed over a number of sites or aggregated at a particular source including a hand-held device. The information is organised primarily to support continuing, efficient and quality health care. The record is under the control of a known party.**

**FIGURE 1.**

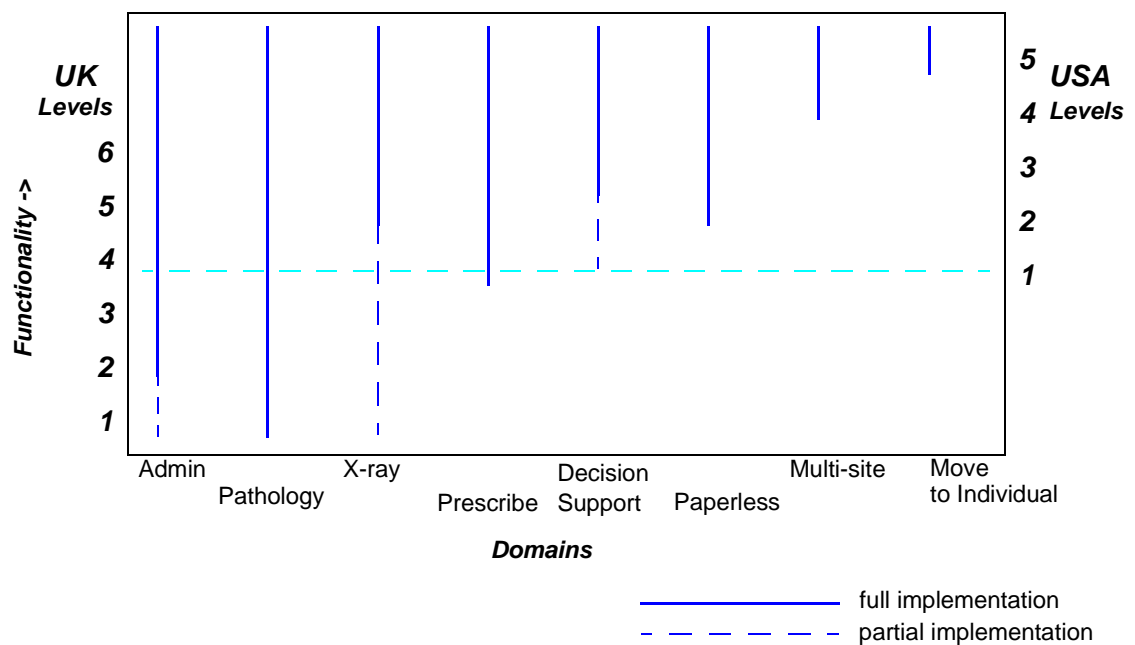
The electronic health record after Murphy et al.<sup>5:p7</sup>.



The Electronic Health Record (EHR) is an unusual concept - it is a record, a set of data - but it is not accessible without a computer system to interpret it. EHR systems provide the mechanism for the communication of records or part thereof, a feature which differentiates such systems from stand-alone medical record systems<sup>1</sup>. EHR systems operate in a defined technical environment with organised and interoperable components enabling management of and efficient access to information by qualified users via a graphical and potentially interactive multimedia user interface. Having launched an EHR within a system, the data within the EHR can at once be manipulated, viewed in different ways and processed into information which assists in the provision of health care. EHR systems also ensure security of the record and the confidentiality of personal health information.

EHR systems vary in their level of complexity - from a simple application offering reminders to a health professional in their day to day work to complex multimedia systems recording data continuously in an intensive care unit. In both the UK and the USA efforts have been made to classify the levels of EHR implementations - levels 1 to 6 in the UK and 1 to 5 in the USA. Names have been suggested for the levels in the USA but using these will only add to the confusion over names. The USA criteria are more stringent than the UK as expressed in Figure 2 below. Thus a level 4 system in the UK is about the same as a level 1 system in the USA as shown below - both will have full patient administration and pathology, partial radiology (reporting only) and electronic prescribing with some decision support (e.g. medication interaction checking).

**FIGURE 2.** Levels of EHR implementation



### 3.1.2 THE 'BOUNDARY' OF THE EHR

The Good European Health Record Project<sup>6</sup> introduced the concept of the boundary to the electronic health record. It is important to accept that if a patient is to have control over the EHR, and if a clinician is going to be accountable for the use and content of the EHR, then it must be absolutely clear to all parties what is and what is not in the health record. Gordon et al<sup>7</sup> have also approached this problem in a hospital system environment. For the purpose of this document an EHR is all recordings entered or accepted by a responsible clinician regarding the care of that patient. Thus, information does not form part of the health record until a clinician has taken responsibility for that information and entered it into the record. In the future it is likely that this will extend to patient themselves being able to enter information directly into their records. Controls will be required so as not to invalidate rules by which important and automatic processes such as decision support operate.

### 3.1.3 THE PURPOSE OF AN ELECTRONIC HEALTH RECORD

The electronic health record is an important tool supporting quality health care. Just as there will be many different situations in which it is accessed, the record can play many roles in the provision of care to individuals and to populations. The following list of

functions of the EHR is based on a list from Shortliffe et al.<sup>8</sup>, GEHR<sup>9</sup>, *Health Online*<sup>2</sup> and the ScopeEPR project<sup>4</sup>.

***Supports  
consumer  
involvement***

- Protects personal privacy and reinforces confidentiality
- Provides a consumer view of information
- Accommodates consumer decision support and self care
- Ensures accountability of health professionals
- Accesses information for the consumer

***Supports  
consumer health  
care***

- Forms the basis of a historical account
- Anticipates future health problems and actions.
- Describes preventative measures
- Identifies deviations from expected trends
- Accommodates decision support

***Supports  
communication***

- Supports continuing, collaborative care and case management
- Accesses medical knowledgebases
- Allows automatic reports
- Supports email generation and electronic data interchange (EDI)
- Enables record transfer
- Enables record access when and where required
- Supports selective retrieval of information

***Supports  
management and  
quality  
improvement***

- Enhances the efficiency of health care professionals.
- Supports continuing professional assessment
- Facilitates management tasks and reduces routine reporting
- Demonstrates and improves cost-effective practice
- Accommodates future developments
- Provides a legal account of events
- Provides justification for actions and diagnoses

***Supports  
population health  
care***

- Supports policy development
- Provides evidence for development and evaluation of programs

***Supports enquiry  
and learning***

- Supports clinical research
- Assists with clinical audit
- Supports medical education

These functions must be carried out in an environment of trust - aiding appropriate sharing of and access to information while posing the absolute minimum risk to personal privacy. The privacy and security of health information is of paramount importance to all consumers - breaches will damage consumers and their trust in the health care system and should be the target of appropriate sanctions.

**3.1.4 REQUIREMENTS  
OF A HIGH  
QUALITY  
ELECTRONIC  
HEALTH RECORD**

Clinicians and patients need high-quality information systems to connect an individual person or health record to a repository of knowledge that is relevant to the care provided. This should include relevant background information about the patient, drawn from a range of individual health records across the health service and evidence-based management protocols that can be directly applied to the care of individuals. A key enabler for this is a longitudinal, person centred and pan-enterprise EHR.

Good health records are not just a scattered accumulation of health related data about individuals. Entries are made as formal contributions to a growing and evolving story, through which the authors are accountable for health care actions performed or not performed. At any point in time a patient's health record provides the information basis against which new findings are interpreted, and its integrity, completeness and accessibility are of paramount importance.

***Comprehensive***

A comprehensive electronic health record needs to capture all of the necessary health care information traditionally held in physical records, including:

- free-text, term set (coded) entries, with qualifiers, synonyms and abbreviations
- units of measurement, normal ranges and accuracy
- radiological images and bio-signals
- templates and standard data sets, derived from guidelines of best practice
- charts, tables, drawings and diagrams
- drug prescriptions, standard letters and reports, patient summaries
- alerts, prompts and reminders

***Structured data***

Clinical practice requires a rich and varied vocabulary to express the diversity and complexity of each patient encounter. An EHR system must be underpinned by a common terminology to express clinical content, that can accommodate such freedom of expression, whilst supporting the need for structured and semi-structured interpretation of each entry.

***Organised  
information***

A comprehensive EHR must enable statements to be grouped together under headings and sub-headings in a clinically meaningful way. Aspects of certainty, severity and the absence of findings must be capable of rigorous and unambiguous representation. For example, a patient with only a family history of diabetes or in whom diabetes has been excluded must not erroneously be retrieved in a database search for diabetic patients.

***Medicolegally  
acceptable***

Electronic health records must be medico-legally acceptable, for example as legal evidence, with a rigorous audit trail of authorship and amendments. They must be implemented within a formal security and access framework that ensures only the appropriate persons connected with the care of the patient can retrieve and edit their record. Health care information must be transferred between sites in a secure manner, maintaining integrity and complying with regulations and legal requirements.

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**3.2 PRINCIPLES**

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The following guiding principles are based on those in the *Health Online* report and are used to underpin the conclusions of this report.

- Consumers, providers and managers are encouraged to innovate in appropriate use of information and communication tools.
- Information which is collected about individual health consumers is transferred and used with their knowledge and authority.

- Health consumers and providers are engaged at all stages of planning and development of new information services.
- The public and individual interests will be protected - particularly in relation to privacy.
- The rule of access to the EHR will be accepted as being defined by the principle of duty of care and explicit consent by the individual consumer.
- Information needed for research policy and planning purposes should be generated as a by-product of operation of systems primarily designed for supporting health care delivery.
- Governments should concern themselves with leadership, direction setting and providing encouragement to the private sector, health providers and consumers to participate fully in the information economy.
- Planning and coordination should be undertaken at a national level to ensure a high level of coherence and consistency, and to eliminate duplication and waste.
- The costs and benefits of proposals to improve information management are assessed to ensure a value for money approach to investment.
- In order to take a national approach it will be necessary for some agencies to control some aspects of the domain and the means of development.

### **3.3 CHARACTERISTICS OF THE AUSTRALIAN HEALTH CARE ENVIRONMENT**

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Some features of the Australian health care environment will influence aspects of the implementation of EHRs. The major features considered in this analysis are listed under characteristics of the population, characteristics of the health care system and characteristics of health care information systems.

#### **3.3.1 CHARACTERISTICS OF THE AUSTRALIAN POPULATION**

Australia has an increasing proportion of older people in the population, with people aged 65 and over comprising 12% of the population in 1998 and projected to make up over 20% of the population by 2031<sup>10</sup>. People favour living in urban areas. In 1996 70.4% of the population lived in the metropolitan areas, 26.3% in rural areas and 3.4% in remote areas<sup>11</sup>. Over half the area of the continent contains just 0.3% of the population<sup>12</sup>. The Australian population is multicultural. In 1996, 2.5 million people (or 15%) aged 5 or over spoke a language other than English at home<sup>10</sup>. Australians are heavy users of health services and have changing expectations; they expect more choice, greater accountability, higher quality, more affordable services with easier of access, greater equity and a more self care and autonomy.

Particular identifiable groups in the Australian population have poorer health outcomes than expected - the most pressing of these are Indigenous Australians.

#### ***Information and the internet***

In November 1999, 25% of Australian households had home internet access, an increase of nearly 37% on November 1998. Six million adults or 44% of the adult population had accessed the internet at some time during the 12 months to November 1999, compared with 31% of adults in same period the previous year<sup>13</sup>. People are generally seeking greater access to health information (including that held about themselves) to enable them to make informed decisions and exercise control over their own health and well-being - and are looking to the internet to provide this information. However, use of computers and internet usage amongst the Australian population is uneven, drawing attention to problems of access and equity. Data from the Australian Bureau of Statistics indicates that men are more likely to use computers and access the internet at home



than women. Among adults aged 18 years and over 14% of men and 8% of women used a computer daily<sup>10</sup> and in the 12 months to November 1999 48% of men compared with 39% of women had accessed the internet<sup>13</sup>.

**Internet usage**

Internet usage is highest amongst young people and lowest amongst older people with 73% of 18-24 years having used the internet in the 12 months to November 1999 compared with 16% of people aged 55 and over<sup>13</sup>. Internet usage is highest amongst people living in capital cities. In 1998 48% of capital city households had a computer and 19% of householders had accessed the internet from home compared with 38% and 11% respectively for households outside of the capital cities<sup>10</sup>. Households with higher incomes are more likely to have a computer and internet access<sup>10</sup>. Adults with a higher level of educational attainment are more likely to be internet users and the presence of children in a household is a key determinant in the decisions to acquire a computer or internet access<sup>10</sup>.

It is important to recognise that women and the elderly are at present low users of the internet and high users of health services. Parents of young children, who also require more health care, are more likely to have internet access.

**3.3.2 CHARACTERISTICS OF AUSTRALIAN HEALTH CARE SYSTEM**

Health care in Australia consumes 8.5% of the gross domestic product (GDP) - about \$43 billion in 1998 - which is slightly under the OECD average<sup>2</sup> -. Only about 45% is funded by the Commonwealth Government, with 32% from the private sector and 23% through States' and Territories' revenue.

Some aspects of the Australian health care system have implications for a national approach to electronic health records:

- the consumer has the choice of provider when seeking care;
- there is a mixture of independent and government providers;
- Indigenous community controlled health services provide accessible and appropriate health care to Indigenous people;
- the general practitioner is the primary provider of medical care and acts, in most instances, as a gatekeeper for access to investigations and specialist care;
- there is, increasingly, a partnership between patient and health care professional;
- allied health professionals are taking a greater role;
- consumers increasingly seek care from alternative health practitioners;
- the rapid increase in the number of new services and products from research and via new technologies, results in new information types and recording requirements; and
- inequalities in health care and outcomes continues to be a problem among disadvantaged groups, particularly Aboriginal and Torres Strait Islander peoples.

Alternative models of funding and care provision have been evaluated in the form of 'co-ordinated care trials' throughout Australia - the products of this work are soon to be available. 'Blended payments' - a mixture of fee for service and incentive payments - are now the basis for remuneration in the independent primary care. These funding models both require information handling and offer a means of funding it. The Practice Incentives Program (PIP) has altered the acceptance of computer assistance in practice management and prescribing in primary care through new incentive payments. The rates of computer use have increased dramatically since the PIP has been operating in Australia. In February 2000 sixty-five percent of general practices which had enrolled

in the PIP are using electronic prescribing and 79% of GPs are claiming payment for access to email and the internet.

### **3.3.3 CHARACTERISTICS OF HEALTH INFORMATION SYSTEMS**

Some aspects of health information systems used in Australia that have implications for a national approach to electronic health records are:

- the principle of ‘duty of care’ dictates access to the health record;
- increasing computerisation of general practice in an uncontrolled environment;
- increasing electronic messaging between providers – especially pathology;
- HL7 messaging has been accepted as a standard by Standards Australia but is not yet widely used in communications;
- a diverse range of hospital systems are in place with limited clinical information beyond test results in most settings and there is no fully integrated EHR in Australia’s inpatient setting<sup>14</sup>;
- hospital systems are generally built from a number of providers (best of breed); and
- expansion of information and telecommunication technologies in health care delivery as described in *From Telehealth to E-Health - The Unstoppable Rise of E-Health* (1999)<sup>15</sup>.

## Part 4 Benefits of an Electronic Health Record



The benefits of electronic health record systems are discussed in this part of the report. It must be stated from the outset that the body of scientific evidence demonstrating benefits from the implementation of an EHR is not overwhelming. Much of the evidence is gained from the computerisation of different clinical processes in isolation - almost always without a true EHR. However, it is virtually certain that the clinical benefits that have been demonstrated will be substantially greater when these computerised processes work with a longitudinal EHR. Likewise, the economic benefits will be substantial when all processes are computerised<sup>16</sup>.

### ***The nature of the evidence***

Methods for determining the level of benefit vary in type and quality. A systematic review of empirical evidence in primary care over 10 years to 1994 uncovered 30 papers<sup>18</sup> and a similar review of evidence in a hospital setting over 5 years to 1995 revealed 55 papers<sup>19</sup>. The most recent review of clinical decision support in 1998 showed more studies were being conducted, and that the studies themselves are of higher quality<sup>20</sup>.

It is worth noting that almost all research has been done on systems that are not commercially available<sup>21</sup> and hence there is no certainty that the same functionality can be delivered in a commercial environment.

We have classified the evidence for benefit in the following manner:

- *Empirical (E)*- the results of scientific enquiry or formal evaluation which has been consistent across different implementations;
- *Priority (P)*- although this benefit has not been demonstrated empirically, it is widely accepted as a benefit of true EHR implementation and a high value is consistently placed on this by stakeholders as evidenced through research, evaluation or repeated expression in publications;
- *Financial (F)*- cost-effectiveness has been demonstrated (or not) using financial modelling, and;
- *Theoretical (T)*- benefit that is expected to accrue in the opinion of experts, based on their knowledge and experience of the area.

Grades of evidence for benefit are given within each category:

- *Grade 1* – well documented and research methodology accepted unanimously by the consultants
- *Grade 2* – Adequately documented and methodology accepted by at least 2/3 of team
- *Grade 3* – not adequately documented but accepted by at least 2/3 of the team

This will be presented in the text in the form of a letter and number classifying the evidence simply. For example:

[E1] meaning scientific evidence which is well documented; or

[P3] meaning high stakeholder value, poorly documented but felt to be important by 2/3 of reporting team.

Different benefits will accrue at different levels of implementation of the EHR system. The NHS executive in the UK have attempted to delineate these benefits at the different levels of implementation in secondary care<sup>22</sup>.

#### 4.1 A GREATER CONSUMER FOCUS IN HEALTH CARE

Much of the evidence in this section is drawn from documents<sup>23, 24, 25, 26, 27, 28, 29, 30, 31, 33</sup> produced or referenced by key consumer organisations.

Increased access to education and dual incomes has meant that there is a generation of consumers who are ready, willing and able to take advantage of the new information age. They are interested in health, willing to challenge health professionals and question the basis for their advice.

**TABLE 1.** Driving forces, in *The Future of the Internet in Health Care*<sup>34</sup>

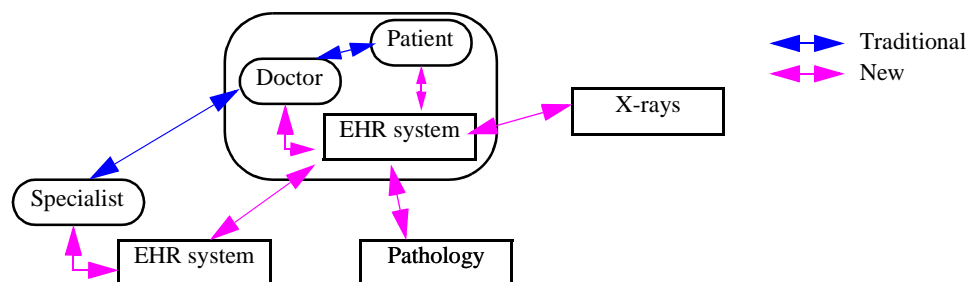
Driving forces from a consumer perspective	
21st century health care consumers	• Cash, College, Computers
Experience with other industries	• internet shopping and email
Characteristics of the internet	• Cheap, easy to use, democratic, not constrained by distance, increasing functionality
Market forces in health care	• exposure of health care to usual market forces

##### 4.1.1 A MORE ACTIVE ROLE FOR CONSUMERS

• *Evidence: E2, T2.* The changing nature of health care is evident to all. Patients increasingly come to the consultation with information about their health problems or the diagnoses they consider to be likely. Their ideas may be based on the results of a medline search or from a website they have accessed through the internet. The consultation is also changing<sup>4</sup>. The computer, present at the time of consultation, offers the possibility of accessing information very rapidly. It becomes the third party in a triad - the patient, the doctor and the computer - working to maximise the benefit to the patient and the efficiency of the interaction.

FIGURE 3.

New 'relationships' in the world with EHRs



Timely and appropriate access to and exchange of EHRs can empower consumers<sup>32</sup> and facilitate a greater consumer focus in health care<sup>35,36</sup>, a stated objective in *Health Online*<sup>2</sup>: p12:

*Health consumers should be able to access their personal health information and it should be accessible across different services and across national and international borders in the interests of their own health care.*

However, consumer benefits will only be maximised if, in the process of gaining access to their EHRs, their privacy and security needs are adequately safeguarded<sup>37</sup>. Consumers, therefore, need to be in a position to control and monitor the access and contents of their EHRs; including control of disclosure of data appropriate to the type of care received.

#### **Consumers involved in creating the record of care**

Consumers need to be directly involved with creating their health records - for a number of reasons. First, the patient's perceptions must be captured in the record in order to measure outcomes subsequently<sup>38</sup>. Second, patient information needs to be reviewed for accuracy and completeness. Paediatric records have been shown to be more accurate and complete when parents were given access to enter information directly into the record<sup>39</sup>. Finally, direct involvement in their records may improve patients' health. Liaw's study of computer generated patient held health records concluded that the patient held record is "an important determinant of patient participation in information and responsibility sharing, health promotion, and disease management"<sup>40</sup>. Patients can be productively involved in negotiating the outcomes sought from clinical interventions and can tailor computerised decision support to their situation and need<sup>41</sup>. As the Consumer Focus Collaboration Strategic Plan<sup>42</sup> notes:

*There are many studies which show a positive relationship between more active consumer involvement in their own health care, supported by the provision of health information, with improved health outcomes. Moreover, evidence suggests that consumer access to their health records can have therapeutic benefits for consumers.*

There is increasing evidence that EHRs are accepted by consumers<sup>43</sup>. A systematic review of general practitioner consulting suggests that consumer satisfaction is not affected when the clinician uses a computer<sup>18</sup>. However, patient initiated activity may

be reduced with a computer present as the clinician's agenda is extended by access to information, although this may be offset by better clinician performance.

**Online access**

When given the ability to access their own health records online - almost all consumers take up the opportunity<sup>44</sup>. Three quarters of the consumers in the study were most interested in the historical aspects of their health care. Enabling on line access will require, at least in the short term, more time from health professionals. One in four problems as entered in the record required more information from the clinician and one in four patients had queries about possible inaccuracies.

**Consumer view of EHR**

Efforts have already begun to overcome some of these problems with a consumer axis, or view, of the NHS Clinical terms (or Read codes)<sup>45</sup>. Clinical terms are presented in language use by the public: for example, a term such as "anterio-inferior myocardial infarction" is presented as "heart-attack". Software tools can be built to offer an online explanation of the EHR, tailoring the information to that particular patient<sup>46</sup>.

Consumers have demonstrated some preference for hand held computers - especially when they are entering information<sup>47</sup>. There is a preference for receiving written information - particularly patient information leaflets<sup>48</sup>. The EHR will enable personalisation of this information in the future.

**• Implications for a national approach in Australia**

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- ◆ The drivers for consumer access to the EHR are:
    - provision of individually tailored information for the consumer;
    - correcting and adding to the content of the EHR;
    - gaining an understanding of their health in historical terms;
    - assisting in informed decision making and reviewing current management;
    - enabling improved and evidence based self-care; and
    - through access to information, the development of greater trust between consumer and health professionals.
  - ◆ With access, EHRs are widely accepted by consumers as a valuable resource in achieving and maintaining health. Consumers are far more likely to access them online if this is possible, rather than at the time of consultation. Interaction in a clinical setting may be more acceptable with small hand held devices which are more private and less intimidating. Touch screens have been found to be most acceptable to consumers in the UK<sup>49</sup>.
  - ◆ Clinical terminology used at present is not straightforward from a consumer perspective and efforts are required to ensure there is a consumer axis for terminologies used in clinical care.
  - ◆ If consumers are to use the record then they will want to have some say in the design of tools for that purpose. A set of guidelines for involving consumers in EHR development and utilisation is required and research and development of tools to aid consumer access to and utilisation of their personal health information.
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**4.1.2 INFORMED  
DECISION  
MAKING**

• *Evidence: T2.* EHRs enable consumers to become better informed about their health care, particularly since the information and communication benefits of the internet make it easier for consumers to find out how to care for themselves, develop a better understanding of their diagnoses and make informed choices about their treatment options<sup>50</sup>. As a report by the RCGP Health Informatics Task Force in the UK<sup>4</sup> states:

*The influence of the information society has already led to the rise of the citizen as an active consumer of knowledge, enabling them to participate actively in situations where previously they were passive recipients. This is likely to extend to healthcare, as soon as publicly accessible health information infrastructure comes into being.*

It is estimated that at least 100,000 websites have health related content<sup>51</sup>. Furthermore, the internet makes it easy for consumers to access information from other countries as well as their own.

*For the first time in the history of medicine consumers have equal access to the knowledgebases of medicine<sup>51</sup>.*

**Consumer online  
resources**

For example, consumers may access:

- Medline, the online database of the National Library of Medicine in the USA through Pubmed, a free access search engine, established in 1997 (<http://www.ncbi.nlm.nih.gov/PubMed>). PubMed enables consumers to search the 15 million citations and abstracts from over 3,900 bio-medical journals that are contained in the National Library of Medicine. More than 50,000 people visit PubMed each day and an estimated 325,000 searches are made daily. Moreover, the National Library of Medicine estimates that non professionals conduct about one third of all searches in the system<sup>50</sup>.
- The Virtual Hospital website of the University of Iowa (<http://www.vh.org>). This website has 35,000 pages of information for health professionals and patients and it attracts about 4 million hits a month. Although it was set up with a clear distinction between the information needs of the public on the one hand, and of health professionals on the other, this distinction has broken down and it is estimated that consumers conduct 70% of the searches of the Virtual Hospital website<sup>50</sup>.
- The Canadian Arthritis Society's website (<http://www.arthritis.ca>) has more than 14,000 pages available for physicians, researchers, other health professionals and consumers. The website is maintained by professionals and volunteers and receives more than 12,000 hits a day, with 40% of them originating outside of Canada<sup>52</sup>.
- HealthLink, a consumer information resource, established by Sydney's Westmead Hospital in 1986. HealthLink provides online and disk based information on health services, infrastructure and books.
- Various online support groups provide support and advice about particular medical conditions and diseases for both patients and their carers. A recent report by the Benton Foundation in the USA suggests that consumers may find it easier to attend electronic chat groups, bulletin board systems and online forums than face to face meetings<sup>50</sup>.

A number of guidebooks are now available which help consumers and health professionals find health related websites. For example, *Webdoctor*<sup>53</sup> and *How to find Health Information on the internet*<sup>54</sup> briefly describe health related websites providing information on fitness and diet, children's, men's and women's health, sexuality and fertility, substance abuse, aging, long term care and rehabilitation, biomedical education, prescription drugs and medicines, plastic surgery, dental care and alternative medicines, as well as sites covering specific diseases and conditions.

EHRs can also be linked to computerised information databases enabling health providers to deliver personalised health information to consumers at the point of care. Information about an illness, medicine or treatment can be printed out for a patient to take home and refer to later. A trial undertaken in a large oncology unit in Scotland found patients preferred information that was individualised by a link to their medical records<sup>4</sup>. Furthermore, a 1996 USA survey found that consumers ranked "information from my own doctor's office" as the type of online health information that they desired most<sup>55</sup>. Many patients are also interested in exchanging emails with their doctors, something that has only recently become a reality for general practitioners<sup>57</sup>.

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**• Implications for a national approach in Australia**

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- ◆ Accreditation of providers of health information online will assist consumers in their choice and handling of the material offered. Institutions such as the Health Issues Centre (<http://www.vicnet.net.au/~hissues>) are developing websites for this purpose. Seamless integration of access to such online material should be a feature that is allowed for in Australian developments.
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**4.1.3 EHRS CAN IMPROVE THE HEALTH OF UNDERSERVED POPULATIONS**

• *Evidence: E3, P2.* EHRs can improve the health of underserved populations. Studies of computer use in UK general practice which were conducted in deprived populations have shown more results consistent with improved care than in the general population<sup>18</sup>. This may represent increased opportunistic case finding in this setting. Couzos<sup>56</sup> in the Kimberley and Fraser in Arnhemland have demonstrated increased recruitment of high risk Aboriginal women for routine Pap test screening through use of a computerised process tool. Health professionals working with homeless populations have also found EHRs improve the care offered in this setting<sup>59,60</sup>.

Information technology also makes the delivery of health information in languages other than English cheaper and easier. In South Australia the Migrant Health Service is using video-conferencing technology to provide more flexible and less expensive interpreter services than previously<sup>61</sup>.

Similarly, EHRs assist the delivery of telemedicine, of particular benefit to both providers and consumers in remote areas of Australia. As a 1999 report by the European Group on Ethics in Science and New Technologies to the European Commission<sup>58</sup> suggests "The EHR opens the possibility of telemedicine in which a practitioner can give a consultation without the physical presence of the patient". EHRs also facilitate the development of tele-homecare, enabling patients to remain in their own homes with monitoring and support systems that interact with their personal health records<sup>1</sup>.



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**• Implications for a national approach in Australia**

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- ◆ Monitoring of service in different contexts is important to ensure equity of access to EHR services across the Australian health service.
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**4.1.4 IMPROVED ACCOUNT-ABILITY IN HEALTH CARE**

• *Evidence: E2, P2.* From a consumer perspective, EHRs can facilitate a consistent approach to the monitoring and reporting of the outcomes of care by provider organisations<sup>62</sup> and avoid problems relating to the legibility of hand writing in paper based records<sup>63</sup>. Moreover, studies indicate that when consumers are given access to their medical records the quality of record keeping improves<sup>39</sup>. As Carter<sup>42</sup> points out:

*Access to their medical records makes consumers more comfortable with their distribution...access is not just about privacy, but also facilitating communication, informed consent to treatment and quality of healthcare.*

With right of access to their medical records consumers are able to:

- check the accuracy of their records<sup>64</sup>;
- supplement the information contained in their records<sup>62:p15</sup>;
- make informed decisions about whether to give or withhold consent concerning the use of their records<sup>64</sup>;
- review the 'log' or who has gained access to their record<sup>65</sup>; and
- make informed decisions regarding complaints they may want to make concerning their health care<sup>64</sup>.

Interestingly, despite concern by consumer advocates in the UK, there has been no litigation concerning access to health records and little demand from consumers to formally access their own records<sup>66</sup>.

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**• Implications for a national approach in Australia**

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- ◆ Consumer access to EHRs is critical to good functioning of those records and trust between providers and consumers.
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**4.2 IMPROVED HEALTH OUTCOMES**

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• *Evidence: E2.* Consumers must benefit from the introduction of the EHR. Ideally this benefit should include better health<sup>67</sup> - not just the provision of more efficient and cheaper health care - to better informed consumers. There is some evidence that this can be achieved. Researchers have addressed this issue in detail in some systematic reviews and the number of papers published each year on this topic is increasing<sup>18, 20, 19, 41</sup>.

Much of the work that has been carried out involves specific disease states and particular computer programs to assist in patient care. For example, in an early randomised controlled trial, computerised feedback on hypertensive care by general practitioners led to a reduction of 5mm Hg of diastolic blood pressure and 4 fewer visits per year in the intervention group<sup>68</sup>. Computerisation of diabetic care was reviewed by Balas and

colleagues and found to have been beneficial in 12 of 15 of the more rigorous trials. The outcomes achieved were better control of blood sugar and also a lower frequency of dangerous low blood sugar levels<sup>69, 70</sup>.

**Preventing  
adverse events**

Adverse drug events are the most common type of iatrogenic injury and probably occur in a serious manner at a rate of approximately 7% of hospital admissions<sup>71</sup>. Three patients per 1000 admitted to hospital will die and one will suffer serious long term disability due to adverse drug events - and it is thought that as many as 78% of these may be prevented by improved information systems<sup>72</sup>.

Patients can benefit from a shorter length of stay in hospital as a result of improved care. A before-after study undertaken in an Intensive Care Unit with a clinical decision support tool to assist in the use of appropriate anti-infective prescribing (largely of antibiotics) reduced overall length of stay significantly. This study<sup>73</sup> demonstrated that the computer assistance led to:

- a reduction of orders for drugs to which the patient was known to be allergic (35 v 146,  $p < 0.01$ );
- a reduction of excess doses (87 v 405,  $p < 0.01$ );
- a reduction of prescriptions to which the infection was not susceptible (12 v 206,  $p < 0.01$ );
- a reduction in the mean days of taking the excess dosage (2.7 v 5.9,  $p < 0.002$ );
- a reduction in adverse events caused by infective agents (4 v 28,  $p < 0.02$ );
- a reduction in the length of hospital stay (2 days,  $p < 0.001$ ).

**Reducing length  
of hospital stay**

The reduction in length of hospital stay was achieved with considerable savings (although it is this aspect of the study that has been criticised most). Earlier studies by the General Accounting Office (GAO) in 1991 support these findings with a reduction of average hospital costs of US\$600 - because of shorter length of stay<sup>3:p53</sup>.

A systematic review of clinical decision support<sup>20</sup> showed that out of 68 studies only 14 assessed patient outcomes. Of these only six showed any effect - all positive. Of the remaining 8 studies only 3 had a power of greater than 80% to detect a clinically important effect.

On a different note, Ogushi and colleagues in Japan<sup>74</sup> have investigated and evaluated public health programs initiated on the basis of information derived from a regional health database linking hospital health records. They have shown some success in altering behaviour (e.g. exercise, alcohol consumption) and health parameters (e.g. liver function tests) in groups through specific health education for consumers and health professionals.

**• Implications for a national approach in Australia**

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- ◆ Meaningful and valid evaluation of EHR implementations is required to monitor the benefit and harm to consumers and their health.
- ◆ The expertise and capacity to carry out this work needs to be developed and maintained in a form that is likely to serve the interests of consumers.

- ◆ Studies that measure patient outcomes need to have sufficient (statistical) power - an issue that may have funding implications and needs to be brought to the attention of the NHMRC.
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### **4.3 IMPROVED AND APPROPRIATE ACCESS TO HEALTH RECORDS FOR HEALTH PROVIDERS**

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EHRs make possible simultaneous access by different health professionals at multiple sites<sup>75</sup>, an important benefit as "health care services have become highly specialised and providers often work closely in multi-disciplinary settings" <sup>64:p12</sup>. In a recent article in the Victorian newspaper, *The Age*,<sup>78</sup> Professor Bob Douglas, from the National Centre for Epidemiology and Population Health, describes the present fragmented paper-based record system as a "formula for failed management and fatal mismanagement":

*Our health record system in Australia is dangerously inadequate because so many different professionals in so many different settings are now involved in the health care of different patients... Doctors and other health workers are often unaware what care has been given by others to the patient before they see them and, unless the patient has a prodigious memory and can explain precisely what others have done for them, they have no way of finding out.*

Electronic records can be promptly accessed from any location, even internationally, across a communication link or network. This is an obvious benefit to Australian people, many of whom are increasingly mobile, travelling away from home for work and leisure purposes. In particular, the ability to provide quality emergency care is improved by the rapid transfer of health information that the EHR makes possible<sup>62</sup>.

#### **4.3.1 THE ABILITY TO SHARE PATIENT DATA AMONG DIFFERENT SITES WITHIN A HEALTH CARE SYSTEM**

• *Evidence: P1.* Linkage of health records for a particular patient from different health record sources is possible with EHRs in a way that is not available to paper records. Records kept at different sites, or within a health care facility, can be linked, merged and shared to create a single 'virtual' health record. There are two approaches to providing this facility. First, the data from different systems may be aggregated in real time and displayed to the patient and health care professional - this approach is called a federated system approach. Second, the information may be stored in such a way as to enable aggregation at the information storage level - this approach is called a standard health record architecture. Both approaches ensure that comprehensive health information can be shared between providers - all graphic data (e.g. x-rays), correspondence and reports (e.g. referrals) and signal data (e.g. heart sounds) relating to a patient can be viewed within their electronic record.

Both health care managers and administrators (72%) and health care professionals (73%) rated the ability to share patient data as the highest priority implementation issue in the Medical Records Institute's ongoing EHR survey<sup>76</sup>. This is because it is most likely to remove frustration and lead to real efficiency savings. Patients are also likely to benefit from less delays, less repeats of tests and more appropriate care when clinicians readily have their EHR available. Sharing records was identified as a key benefit to hospitals in the UK Audit Commission Report<sup>77</sup> stressing the belief that ongoing care is better supported by community based health professionals.

CareWeb at Beth Israel<sup>79</sup> and others<sup>80</sup> offer real examples of a ‘federated approach’ which allows information held at many sites to be viewed through a web browser. This can then be used as a ‘virtual’ health record and has the advantage of making use of legacy systems - which often store a considerable amount of data. However there are certain pre-requisites<sup>81</sup> to achieve benefit:

- an agreed record structure (database schema);
- shared concepts of professional process;
- a system of unambiguous person identification;
- a core set of information about patients;
- protocols to maintain confidentiality;
- common terminology and coding;
- agreed interfaces between agencies;
- an appropriate information technology infrastructure;
- acceptance by patients; and
- acceptance by clinicians.

Sharing health records must also be considered in the wider context - enhancing team-work and informed integrated care are both major opportunities for benefit from EHR systems<sup>81</sup>. Branger and colleagues<sup>70</sup> describe efforts to share diabetic care with messaging between EHR systems in the Netherlands. They demonstrated greater communication of information, more complete records at each site and a decrease in HbA1c levels - a marker for diabetic control.

Sharing information is now a priority in primary care. Rigby et al.<sup>81</sup> have proposed that an integrated record that supports shared care and managed care is crucial to the work of extended primary care teams providing the prospect of a “shared clinical perception of a patient’s problems and needs.” The authors go on to state that “seamless care is difficult to achieve without seamless information.” This authoritative paper, written from a multi-disciplinary perspective underpins the need to involve all sectors of care in EHR development.

**TABLE 2.** Primary care EHR features, from Rigby et al.<sup>81</sup>

Principles of the primary care team EHR	Options for where the record should reside
<ul style="list-style-type: none"> <li>• One record that can be read and added to by any health professional</li> <li>• One integrated plan for the support of a patient</li> <li>• Unidisciplinary views of the record available</li> <li>• Consumer to control access to sensitive information</li> <li>• Enable monitoring of quality of care and teamwork</li> </ul>	<ul style="list-style-type: none"> <li>• General practice</li> <li>• Community centres</li> <li>• Virtual ‘integrated’ record</li> <li>• Trusted third party</li> <li>• Consumer held</li> <li>• Formal messaging between different systems</li> </ul>

There are major technical difficulties (which are dealt with in Section 5.4 on page 66) associated with the sharing of health information across different systems. Despite

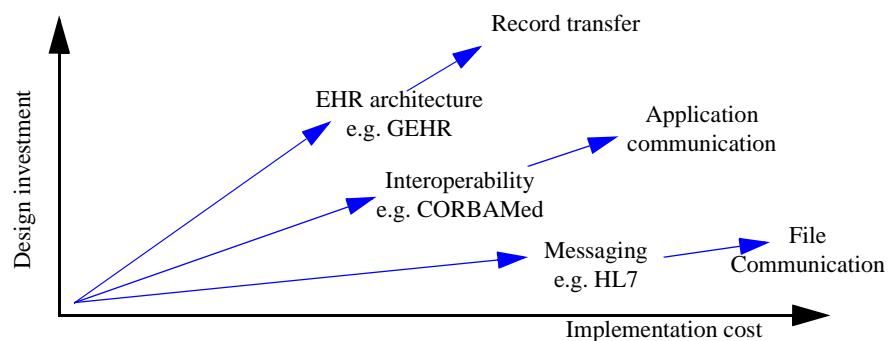
nearly 20 years of development and a major national project to overcome this<sup>82</sup>, a print out of the EPR is all that is available for the future practice when a patient moves and this is often far inferior to previous hand written records<sup>83</sup>. Van Bommel<sup>84</sup> describes a federated or 'virtual' health record approach as an interim means of overcoming these problems. Approaches that describe a standard for the architecture of the EHR, such as the Good Electronic Health Record (GEHR)<sup>85</sup> and the HL7 Patient Record Architecture (PRA) address the issue of sharing information comprehensively.

#### • Implications for a national approach in Australia

- ◆ The sharing of health records has always been limited and remains the major frustration in EHR development to date. Investigating federation of legacy systems through web based technology remains attractive where there is a good deal of commonality.
- ◆ There are a number of initiatives that aim to overcome this barrier of sharing health information in a diverse but complementary manner. The first is simple messaging between systems - HL7 is the leader in this field. Their Patient Record Architecture initiative takes this approach to enable sharing of documents in a machine readable manner and is converging with CEN efforts. CORBAMed is a technical group which aims to allow this sharing to be at a system level without the need for text-based messages (ASCII) and has developed the application interfaces to allow this. GEHR offers a generic EHR information model that further standardises all these efforts by providing a standard architecture for the EHR within the system.
- ◆ Even though the lowest level mechanism for standards has been accepted - HL7 messages - it is not necessarily the simplest as the detailed structure of each message has to be agreed and the means of incorporation into each system has to be developed.
- ◆ However, agreement on and design of a record architecture is also a lengthy process, and while it promises to relieve much of the implementation difficulties and does not dictate the format of the record, this approach is as yet unproven.

FIGURE 4.

Strategies for sharing of health information



**4.3.2 TIMELY AND APPROPRIATE ACCESS TO PERSONAL HEALTH INFORMATION AND RECORDS**

- *Evidence: P1.* A properly designed and implemented EHR can be accessed quickly and securely by any consumer or health professional around the world if the site of care and the EHR source are connected via the internet. This access can extend to 24 hours per day if desired and even via a mobile phone or satellite. This is an objective of *Health Online*<sup>2:p12</sup>.

*Health consumers should be able to access their personal health information and it should be accessible across different services and across national and international borders in the interests of their own health care.*

The NZ Health Information Service (NZHIS) is in no doubt that availability of records will be much greater after the move from paper to the EHR<sup>86</sup>. Increasing health professionals' access to patient records is often used as an argument in favour of EHRs - though this is generally restricted to one site and to the increased access compared to using paper records<sup>87</sup>. Access was acknowledged as a key benefit of EHRs to hospitals by the UK Audit Commission Report<sup>77</sup> - providing easier access to medical history and summary patient details at Admission, in the Emergency Department and Outpatient Clinic.

EHR systems inherently offer increased access to patient data through their ability to search through an electronic record for specific information<sup>88</sup>. Access to information may be particularly important in specific domains, such as in mental health care<sup>89</sup>.

**Data Guardians**

Timely and appropriate access to and exchange of EHRs will benefit consumers, health professionals and managers but poses a great threat to consumers - loss of privacy - and some threat to health professionals who may feel uncomfortable with their records being available to whom ever the patient wishes. The Caldicott Report<sup>90</sup> in the UK has described the role of data guardians - protecting consumers privacy - and states that this should be done by senior clinicians. Training programs have been developed and a manual for registered guardians. These guardians are expected to undertake a program of action which includes<sup>91</sup>:

- a management audit of current practice and procedures;
- annual plans for improvement that will be monitored;
- the introduction of registered access authorisation to certain patient information held outside the organisation; and
- the development of clear protocols to govern the disclosure of patient information to other organisations.

**• Implications for a national approach in Australia**

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- ◆ If consumers are to control access to EHRs, there must be a secure method for this to take place with a trusted senior clinical 'controller' or 'data guardian' at each EHR site. Sources of EHRs must be known and their controllers held responsible for making them available in a secure manner. Further, the mechanisms by which this access will be available must be consistent nationally. The options are messaging, CORBAMed interfaces, Web view and federation of different systems and/or GEHR extract and transfer.

- ◆ Computer systems must be reliable and barriers to access must not be so great as to impede health care.
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#### **4.4 IMPROVED SUPPORT TO PROVIDERS**

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The information in the EHR is static, but can be displayed and processed dynamically and selectively. This allows multiple views of the EHR to be obtained virtually instantly depending on the needs of the provider (e.g. problem-oriented, health summary, medications, chronological etc.) - something that also improves efficiency<sup>92</sup>. Further, the information can be automatically processed to assist the health professional and patient in making decisions.

To achieve maximum benefit from implementing an EHR, four conditions must be met<sup>3:p47</sup>:

- users must have confidence in the data;
- they must use the record actively in the clinical process, at the point of care;
- they must understand that the record is a resource beyond direct patient care; and
- they must be proficient in the correct use of the system.

These conditions must be met before the EHR can be relied on to hold the information required to make safe clinical decisions and support automated processing.

##### **4.4.1 PERSONALISED DECISION SUPPORT**

• *Evidence: E1,F2.* Computerised decision support systems are computer software systems that are designed to aid health professionals when making important decisions. A system usually takes the form of provision of assessments or prompts which are specific to the individual and are selected from a knowledgebase according to their characteristics<sup>41</sup>. Decision support benefits the patient as it provides 'just in time' notification of best practice or possible adverse effects. Clinicians benefit from the convenience of getting relevant information at the moment it is required. Managers benefit from the cost savings potentially associated with evidence based care and avoiding adverse reactions - which are likely to be considerable.

The EHR underpins the success of such systems by providing detailed information on which to base decisions. The EHR needs to be organised in a way that allows safe automatic processing for this purpose. Apart from supporting decision support, the EHR itself can contain prompts and alerts. The Good Electronic Health Record architecture, for example, describes specific information structures that convey key prompts to health professionals opening the record.

To date, the most experience with personalised decision support has been with prescribing. Health professionals are no longer in a position to retain information about all medication interactions<sup>87</sup>. Wyatt<sup>93</sup> has concluded that computerised prescribing improves accuracy, appropriateness, speed and cost of prescribing. His analysis of UK studies suggests that a little over one minute of clinician's time is saved per patient: phoned requests from patients are reduced by up to 38% and there are 5% fewer inquiries from pharmacists. Cost savings of up to 30% have been documented. Accurate records of prescribing increased from 42% with manual systems to 95% with computer assistance.

At the Good Samaritan Regional Medical Centre in Arizona, a comprehensive prescribing support system ‘fired’ 1116 times during 13,521 admissions over a six month period. These alerts identified serious risk to the patient at a rate of 64 per 1000 admissions - 44% of these were not recognised as risk situations by the physician prior to the alert<sup>72</sup>! Further study on the same data showed a 55% reduction in serious non-intercepted prescribing errors - from 10.7 events per 1000 patient days to 4.86 events per 1000. Team review, with its attendant cost and inconvenience, conferred no benefit over the computer assistance<sup>94</sup>.

Decision support can improve adherence to drug formularies<sup>87</sup> by simplifying stock control and clinician information needs. One positive outcome is a reduction in the need to keep track of possible adverse reactions which is now beyond the capacity of health professionals without decision support.

**Generic solutions  
are required**

Most research has taken place in hospital. The more specialised setting makes the design and implementation of such systems more straightforward. In primary care Delaney and colleagues conclude that computerised decision support systems have great potential for primary care but have not addressed the needs of clinicians adequately. These needs encompass far more than just prescribing which inclines to a lack of demonstrable benefit<sup>41</sup>.

Computer assisted *diagnosis*<sup>95</sup>, on the other hand, has made little progress in the last 40 years, and, except for use in very specific situations, is not accepted by clinicians<sup>96</sup>.

As decision support tools process patient-specific data, they offer so much to health professionals and consumers: a promise that is yet to be fulfilled in a generic sense, as at present each tool is tailored to specific clinical information systems and contexts. Ideally, such systems require careful and local evaluation before purchase, something that is not possible due to the fact that decision support systems are, at present, bound to particular clinical software. It is widely accepted that clinical decision support systems will increasingly affect decision making in health care and maximising this benefit is largely dependent on standardisation.

At present comprehensive decision support<sup>72</sup> systems usually operate with no database of medical conditions or problems but simply use demographics, pharmacy orders, drug allergies, radiology orders and laboratory results. A more complete EHR would probably increase the benefit of this system to the patient although it would require a more comprehensive decision support tool.

**• Implications for a national approach in Australia**

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- ◆ Clinical decision support has been demonstrated to make a difference in many areas, but particularly prescribing and prompting for preventative procedures. There is much delay in making such systems available in hospital settings.
- ◆ The EHR requires generic decision support tools, that is to say, tools that can be used in different settings and with different clinical applications. There are three (not necessarily exclusive) approaches to consider for general implementation of decision support:
  - a database of information and an instruction set on how to implement this within each software environment (e.g. Prodigy One, [www.schin.ncl.ac.uk/](http://www.schin.ncl.ac.uk/));



- a standard method for expression of rules (such as the Arden Syntax or GLIF) as all decision support would be written using these ‘languages’ and implemented locally; or
- generic decision support engines (e.g. Prodigy Two) - offered as a standard component for implementation.
- ◆ A standard EHR architecture potentially simplifies implementation issues - the alternative is for every system developer to implement the system in their specific context. This may lead to fragmentation and safety issues that are difficult to assess.
- ◆ The barriers to implementation of these support systems are great - authoring and maintenance of generic guidance requires sophisticated tools that are still being developed. Even with such tools available, authoring is expensive and may only be affordable with international cooperation.
- ◆ Safety of decision support is presently unregulated and issues such as processing EHRs with missing data must be addressed as well as formal evaluation procedures. The topics of research into the performance of clinical decision support have been medication dosage, diagnosis, prevention, disease specific systems (e.g. hypertension or diabetes) and others<sup>20</sup>. This research needs to continue as there is great potential to assist health professionals in offering safe evidence based care in a timely and very acceptable manner.
- ◆ EHRs may exist, but have to be *used* in order to contain sufficient data to support the added functions available with computer assistance.
- ◆ Acceptance of electronic signatures (or other strong user authentication) for prescribing and other orders will further advance the uptake by clinicians and hence the utility of incorporating decision support into these applications.

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#### **4.4.2 ACCESS TO HIGH QUALITY INFORMATION**

- *Evidence: T2.* The EHR can be viewed in many ways and may offer situation specific data to clinicians making decisions<sup>92</sup>. An example is a list of all prior treatments offered for a particular problem or trend graphs for certain key parameters. It will be much easier to make a decision on a patient’s hypertensive treatment when a graph of all blood pressures is offered with line graphs of previous treatments and doses.

The EHR also offers the potential to filter knowledgebases to provide specific information sought by health care professionals or consumers. This advice may be of relevance to the diagnostic process, the patient’s understanding of their disease, prognosis or treatment. The advice may be sought by the patient during the interview, in which case it may be shared at the time, given to the patient as a resource to take away with them or emailed to them for convenience. Health professionals may seek information and retain it as part of the record to inform the patient, a colleague or student in the future or as ‘evidence’ for a decision.

Australia has some high quality independent information on prescribing in the form of the *Australian Medicines Handbook* and *The Therapeutic Guidelines*. Referring to this information is too time consuming for most practitioners - if they can find the books themselves at the moment they are required! Context sensitive information from these sources, including prescribing options, doses and cost are sought by many health professionals.

There is some evidence that health professionals do seek information more often when using EHR systems. This may improve their ability to manage chronic disease<sup>87</sup>. Health professionals and consumers may access scientific publications<sup>97</sup>, particularly if access to the internet is integrated with the EHR<sup>98</sup>. Integrating the EHR with Web and knowledgebase access can lead to efficiency gains as demonstrated by Tarczy-Hornoch at the University of Washington<sup>99</sup>. Integration was achieved at different levels: integration of information by patient, integration of information by provider, and integration of patient specific information with medical reference material and decision support tools. Complex tasks may be assisted with specific tools, such as assessing risk of cancer from family history interpretation<sup>100</sup>.

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**• Implications for a national approach in Australia**

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- ◆ Access to expert knowledge must be fast enough and these days the internet is the only practical alternative<sup>101</sup>. An example might be enabling clinicians to respond to a medication scare in the media that does not give sufficiently accurate information. An email notification with sufficient information as well as expert advice on how to deal with the situation will benefit health professionals and consumers.
  - ◆ For such access to be meaningful there is a need to foster direct internet access by clinicians to rapid response expert opinion, as well as timely access during consultation.
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**4.4.3 ACCESS TO  
CLINICAL  
GUIDANCE AND  
CARE PATHWAYS**

• *Evidence: E2, P2, T2.* While decision support has a demonstrated role in improving the health care of individuals, access to clinical guidance and care pathways promises to deliver more! Consumers stand to benefit from a consistent and evidence based approach to their care by a range of health professionals. Health professionals, on the contrary, may experience some frustration although careful evaluation should demonstrate the risks of not following the guidance.

Access to protocols and guidelines at the time of care was identified as a key potential benefit of EHRs by the UK Audit Commission Report<sup>77</sup>. There is some evidence that this will lead to improved quality of care and ability to manage chronic conditions<sup>87</sup>. EHR systems offer the opportunity to access guidance at the moment of decision making and to have the guidance adapted to that particular individual and linked information and references online.

Experience with such systems are limited as they are still under development. Kaiser Permanente have demonstrated that embedding guidelines in their direct ordering system (EpiCare) improved ordering and lowered cost<sup>102</sup>.

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**• Implications for a national approach in Australia**

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- ◆ High quality resources need to be available, under control of a trusted agency. The UK have done this through the National Institute for Clinical Excellence (NICE). As guidance and care pathways require expert authoring and maintenance this has proved to be a major enterprise. Further, accessing guidance and care pathways is only possible at a system level if the resources are made available in a standard way.
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**4.4.4 ACCESS TO EDUCATIONAL OPPORTUNITIES**

• *Evidence: T3.* In the 19th Century health records were day books or diaries kept by individual clinicians. This approach meant that they could monitor their workload and determine patterns in presentations. The unit record, one record per patient, popular since the first world war, was patient-oriented and supported patient care but made it more difficult to determine trends across a group of patients. In the 1960s Weed<sup>103</sup> changed the focus of record keeping in health care yet again through his seminal paper, "Medical records that guide and teach" - with the aim of supporting patient care and clinician learning. This 'problem-orientated' medical record approach remains popular today.

The EHR enables all these approaches at the same time. That is to say, EHRs can be viewed in different ways by different users and for different purposes. The EHR offers health professionals and students the opportunity to review their records within specific contexts or audit different aspects of care or workload - much as was possible with the early medical records - while still offering the benefit of unit records or problem oriented records. This is considered an important aspect of EHRs<sup>104,87</sup> which will require advocacy to be accepted by consumers.

**• Implications for a national approach in Australia**

- ◆ Appropriate student access to EHRs must be considered important by all consumers and providers, while consumers must have control over student access. This may require raising of public awareness of the importance of educating health professionals.
- ◆ Strategic feedback to clinicians may be possible through third-party tools on, for example, prescribing rates or immunisation coverage.

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**4.5 IMPROVED QUALITY AND SAFETY OF DATA**

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The EHR is quite different than paper records in its ability to validate data at the time of entry and in the multitude of storage mechanisms available.

**4.5.1 IMPROVED DATA QUALITY**

• *Evidence: E3, P2.* When clinical data are added to the EHR and maintained by clinicians who are responsible for care, the accuracy and quality of data is high. Further, when entering data into an EHR, checks can be made to ensure the information is accurate and adequate. Accuracy may be enhanced by querying entries that are unlikely (e.g. heart rate 200-220) or rejecting those that are impossible (e.g. plasma sodium outside the range 120-160 meq/L). Results and reports can be entered directly from other systems, eliminating the possibility of misfiling and of transcription errors. Users' details can also be entered automatically and unambiguously. Data entry becomes a formal process and the system can prompt for missing information<sup>18</sup>.

Kuperman and others<sup>105</sup> have shown that real time computerised charting of nursing care plans and medications using bedside terminals was more accurate than traditional paper techniques. Nurses used their time more productively with this system available.

Completeness of EHR data is now under investigation. With computerised systems the availability of the record is virtually certain (given system reliability). After 5 years experience with an EHR system at the University of Florida hospital, anaesthetists doing pre-anaesthetics checks found that required content of the EHR was not available in 29% of cases. This involved external data in 8% and internal data in the remaining

21% of cases. Surgery had to be postponed in 2% of cases due to lack of information<sup>106</sup>. Paper records are considerably worse<sup>3:p60</sup>!

Finally, there is a necessary trade off between the drive to improve data quality and the acceptability of data entry tools to health professionals - they will have to have the final say but need to be educated in the importance of data beyond the particular consultation.

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• **Implications for a national approach in Australia**

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- ◆ Accreditation of health record systems may involve assessing validation functions to ensure data quality.
  - ◆ Point-of-care data entry is important and will only be undertaken if users are convinced of the benefits of the EHR system.
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#### **4.5.2 IMPROVED DATA SECURITY**

• *Evidence: E2, T2.* Consumers will benefit if EHRs can be more secure and yet more available than paper records. The major risk to consumers in the health care system is unauthorised use of personal health information by authorised users<sup>65</sup>.

With paper records this is particularly difficult to control. Clerical staff typing letters usually have access to the entire record as do staff moving records around a health care facility. Unlike paper systems, EHR systems can monitor access to records by authorised users. Experience at the Mayo Clinic, where many well known patients attend, suggests that close monitoring of record access and a clear policy on disciplinary action will avoid breaches of confidentiality.

Rigby<sup>108</sup> has proposed nine confidentiality principles derived from a patient care based approach.

1. Restriction of access of the EHR to clinicians who *currently* have a duty of care for the individual concerned.
2. It should be possible to assign personally requested special levels of confidentiality to specific health information held in the EHR.
3. EHR availability should be restricted within the organisational boundary within which it is created, except with patient consent.
4. Patients should be advised that supervision of staff and improving organisational performance are part of 'best practice' and may require supervisors to check part of their record.
5. Operational staff (administrative and IT) should only have access to the minimum information required to perform their task. Sanctions for misuse of information should be known.
6. All EHRs should have an automated and tamper-proof audit trail including a log of access which should be available to the patient.
7. The physical machinery storing the EHR should be protected - and patients should be advised of this.
8. Each provider should publish their confidentiality protection policy.
9. Each provider should publish an annual confidentiality audit report.

The major additional risk to privacy from a move to the EHR is from the internet. This is dealt with in "Security of computer systems" on page 61.

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**• Implications for a national approach in Australia**

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- ◆ To protect consumers it will be necessary to ensure that users are authenticated in a stringent manner. This is an issue throughout the computer industry and measures should not be developed specific to the health care environment. Possibilities that are now available include smart cards carried by the user and biometric measurements such as finger print or retina.
  - ◆ The ability to backup EHR data is an important benefit and must not be left to the whim of the EHR controller. National policies of backup for EHR sources should be developed in discussion with controllers, providers, consumers and the software industry.
  - ◆ Accreditation for EHR sources should be considered in light of the need to ensure adequate monitoring of access to EHRs and strong user authentication. Software accreditation will need to address these issues as well as data quality. It is important that the convenience of using EHRs should not be jeopardised.
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**4.5.3 IMPROVED  
STORAGE AND  
EFFICIENCY**

- *Evidence: E1.* It is easy to make multiple backup copies of EHRs<sup>107</sup>, write them onto a small device such as a tape or optical disk which can then be stored in a safe place off site. A CDROM can store 100,000 pages of text or the equivalent of 10 metres of shelf space - a DVD far more.

A large Cancer Centre in New York estimates that space savings from computerising health records is worth US\$100,000 per year, although a more typical saving in smaller centres is US\$4,000 annually<sup>109</sup>.

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**• Implications for a national approach in Australia**

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- ◆ Enabling development of EHR systems in Australia to point where communication can occur without paper will add to savings and efficiencies.
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**4.6 IMPROVED EFFICIENCY AND QUALITY OF HEALTH CARE**

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**4.6.1 PROBLEMS WITH  
PAPER**

- *Evidence: E2.* Paper records are not performing well in the modern health care environment. The Institute of Medicine report<sup>3:p60</sup> summarises in detail the shortcomings of paper records. The EHR can assist in overcoming some of the substantial problems with content, with format, with access, availability, retrieval, linkages and integration.

Murphy and others<sup>5</sup> describe the key insurmountable difficulties with paper records which may be summarised as:

- the record may not be available as it is being used by another practitioner;
- the record is necessarily fragmented as it can only be structured in one dimension - front to back; and
- the record is not useful for audit or research without considerable effort.

Electronic record systems have not abolished the use of paper - although some primary care offices are virtually paperless. In the large and exemplary EHR systems in the

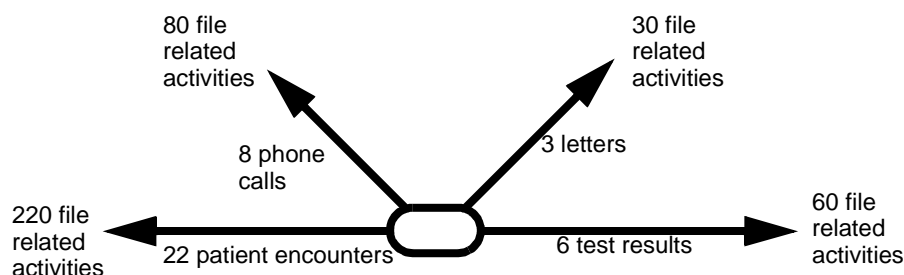
USA none have done away with paper<sup>110</sup>. It may seem paradoxical that at Kaiser-Permanente in Ohio, a system that has got rid of paper charts, there has been an increase in the use of paper because every contact involves printing out a set of computer generated encounter forms - which are then scanned into the EHR.

There are some advantages to paper records in the current transitional situation. First, most users are familiar with them and require little training to get by. Second, they are portable and can be carried by the health professional to the point of care. Third, once in hand they are reliable - they do not crash! Fourth, they allow flexible data entry which is quick and unstructured and finally, they can be scanned quickly.

However, estimates of the percentage of staff time spent maintaining paper records are all above 25% in a hospital setting. Estimates in the USA have been 38% for physicians and 50% for nurses. And, between 35 and 39% of total hospital operating costs have been associated with patient and professional communication activities<sup>3:p63</sup>. In ambulatory care costs have been estimated at US\$3 per patient<sup>111</sup>. This is due to the large number of file related activities per 'event' as shown in Figure 5 below.

**FIGURE 5.**

File related activities per clinician in a model primary care practice in Massachusetts<sup>111</sup>



#### • Implications for a national approach in Australia

- ◆ The national approach should aim to avoid the 'paper paradox' - more technology leads to more paper - ensuring that people have the skills and equipment to write and use information in electronic form.

#### 4.6.2 IMPROVING PROVIDER PRODUCTIVITY AND SATISFACTION

• *Evidence: E1.* This benefit has a lot to do with *not* using paper records! Estimates show that 20-30% of clinicians' time is spent searching for or organising medical information<sup>87,77</sup>. Legibility of the EHR is far superior<sup>107,112</sup>. The ability of the EHR system to provide user dependent data layout<sup>86</sup>, assisted search as well as more output methods (screen, paper, email, fax etc.) and tailored output all aid productivity.

Single entry of demographics and other information used repeatedly reduces transcription expense and reduces billing omissions. Clinical and administrative efficiency is increased by as much as 62%<sup>87,113</sup>, and not only in secondary care<sup>111</sup>. The clinical efficiencies are especially evident in repeat prescribing<sup>18</sup>. Further, there is some evidence of improved quality of service delivery<sup>87</sup>.

Staff satisfaction is increased when tasks are easier. Computer generated discharge summaries have been shown to be less burdensome, faster to generate and preferred to dictation in a randomised controlled trial in Canada<sup>114</sup>. Hunt and colleagues' systematic review of clinical decision support shows almost universal improvement of the health care professional's performance<sup>20</sup>.

Clinicians have views on how EHR systems should be implemented<sup>115, 209</sup>. Taking these into consideration not only aids acceptance of the EHR system but also assists physician learning as a by-product of the implementation<sup>116</sup>. General practitioners in the UK have changed their practice due to the use of computers<sup>18</sup>. There is an increase in doctor initiated tasks which leads to changes such as an increase in immunisations (rates improved from 8 - 18%) and other preventative tasks (up by 50%), improved record keeping and problem list generation. It is worth noting that the improvements do not appear to be sustained at the initial level. Further efficiencies are gained by such facilities as automatic reporting<sup>86</sup> which are dealt with in Section 4.6.4 on page 36.

Achieving benefit cannot be taken for granted. Benefit did not occur where none of the clinicians had an intimate knowledge of the system nor responsibility for decision making during implementation<sup>117</sup>. Benefit is also dependent on having access to computer workstations which are reliable and provide suitable response times.

Butler<sup>118</sup> has reviewed published literature on the impact of Intensive Care bedside computerised documentation systems. These systems lead to a dramatic decrease in the amount of time nurses spend documenting care - usually around 30 minutes per day - and often lead to a much larger increase in the amount of time spent with patients. Annual savings as high as \$196,000 have been demonstrated in one unit.

A study of 500 consecutive patients at the University of Maryland<sup>119</sup> found that computer-assisted support drew Emergency doctors' attention to redundant orders and saved resources and time. Information required by the current clinician was available from:

- the inpatient discharge summary in 85 patients (19%);
- laboratory results in 34 patients (7%);
- pharmacy records in 30 patients (6%);
- radiology reports in 19 patients (4%); and
- electrocardiograms in 11 (2%).

Overall, 120 of 500 patients (24%) avoided redundant tests with a saving of US\$5 per patient.

Experiments to determine whether an automated review of the EHR is possible have been undertaken in the Netherlands and have shown acceptable results<sup>120</sup>.

It is important to acknowledge that some health professionals have particular difficulty using computers which may involve a special kind of dyslexia<sup>121</sup> - a finding confirmed by more general studies of computer users. Mechanisms for these users to gain skills and confidence need to be incorporated into implementation plans. Despite this, there appear to be definite efficiency gains and user satisfaction with some EHR systems, although data entry remains the greatest impediment to this.

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**• Implications for a national approach in Australia**

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- ◆ Improved efficiency and satisfaction is relatively easy to measure with EHR systems. It is an essential feature of successful EHR systems and must not be jeopardised by other requirements. Implications of all other requirements must be investigated in relation to efficiency and user satisfaction and be found to be acceptable.
  - ◆ Efficiency of EHR systems will, to a large extent, depend on their connectivity. If a national approach is to be taken then a threshold level of implementation must be met in order to achieve benefits of efficiency.
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**4.6.3 IMPROVED  
ACCESS TO  
CARE**

- *Evidence: P3.* The evidence for improved access to care is slight and has only been demonstrated in health care facilities with the most comprehensive systems. Kaiser-Permanente<sup>110</sup> have demonstrated a significant improvement in their ability to provide telephone advice through use of their EHR system.

More importantly perhaps, the same group has been able to improve access to specialist care due to the patient administration facilities built into the system. This has led to an increase in the number of people seen within two weeks of referral from 55% prior to implementing the EHR system, to more than 80% following implementation.

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**• Implications for a national approach in Australia**

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- ◆ Monitoring of specialist waiting times can be part of the evaluation of EHR systems.
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**4.6.4 LINKED WITH  
OTHER SYSTEMS  
SUPPORTING  
CARE**

- *Evidence: E1, P1.* Just as efficiency is sought from the EHR system by users, so too is the ability to link to other systems such as billing, referral to (other) specialists, pathology and radiology orders<sup>122</sup>. Consumers may benefit from aspects such as automatic notification to immunisation registers if payments to the consumer are dependent on this information as is presently the case. The major benefits will probably be to clinicians and managers from streamlining work patterns. Anything that speeds processes of care will benefit everybody.

Dealing with referral letters electronically has been addressed in some detail. The potential time saving by administrative staff of using electronic records is estimated at 6 minutes per clinical letter sent or received<sup>123</sup>. With a projected clinical letter rate of about 18 million clinical letters per year in Australia this will save \$36 million Australian dollars per year at \$10 per hour<sup>124</sup>. Estimates in the UK predict savings from full electronic exchange of information to be approximately \$10,000 per general practitioner. Delivery times improve from days or weeks to minutes or hours. Legibility is guaranteed (assuming systems are compatible).

Linking EHR systems was seen as a key potential benefit in the UK Audit Commission Report<sup>77</sup> providing easier access to results of investigations, quicker reporting of results of treatment and easier generation of discharge summaries. Results reporting was perceived as the major benefit in a study of an outpatient EPR system<sup>125</sup>. In a randomised Canadian study<sup>114</sup> comparing database generated discharge summaries and dictated summaries, the database generated summaries were more likely to be generated with



80% completed (at 4 weeks) compared to only 57% of dictated summaries. Further, of those summaries completed, the database generated summaries were also generated in a more timely manner with 95% completed in the first week compared to only 80% of dictated summaries. The summaries were judged to be of similar quality. The quality of the information in computer generated summaries has not been shown to improve despite a number of pilot studies undertaken in Australia<sup>126</sup>.

Automatic generation of recall letters is a successful strategy in primary care, particularly for those who rarely visit a general practitioner<sup>18</sup>.

To achieve these benefits systems require a sophisticated reporting facility and secure communications network<sup>127</sup>.

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**• Implications for a national approach in Australia**

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- ◆ When the links go beyond the current system, communication links and message protocols need to be in place and standardised. The drivers to implement standard HL7 messages are limited in the first instance as shown by the disappointing uptake in Australia so far. There may be a need to drive this implementation: to encourage the early adopters who gain little from their pioneering efforts.
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**4.6.5 COST  
EFFICIENCY**

• *Evidence:* T2. There is a lack of evidence on cost effectiveness that is largely due to the complexity of the task. In the systematic review of benefit in a hospital setting only one paper<sup>19</sup> gave details of costs or benefits to a level required to based future work with certainty. A review of the European literature in 1994 showed only 13 of 108 studies used any sort of economic analysis. Even when costing is given it may not be valid to generalise this gain to other settings.

Methods for determining the true cost-efficiency of EHR systems are being developed and trialed<sup>87</sup>. Overall, financial models support cost savings<sup>128</sup> Financial models by the University of Texas MD Anderson Cancer Centre (USA) predicted a 10 year saving of US\$129.5 million on an investment of US\$54.5 million investment. Kaiser Permanente (Rocky Mountain Division) estimated the financial gain of US \$3.4 million to operations after implementing a clinical information system. Further, analyses predict that the real returns will come from improved clinical management - rather than the present savings on administrative efficiencies.

***Through reduction  
of errors***

Some cost savings are due to changed work practices, such as more communication between primary and secondary care<sup>129</sup>. There is reduced workload in Medical Records departments although the cost can be difficult to ascertain as the IT department will require more staff. Storage capacity in digital format is far smaller than the paper format and will save space<sup>86</sup>.

Cost savings have been described in Section 4.4.1 on page 27 above through the reduction of clinical errors - especially inappropriate prescription of medications leading to more hospital care and possibly death. Further, the access to knowledgebases and performance data should limit patient exposure to unnecessary surgery and consequent litigation and compensation. Also described in Section 4.6.2 on page 34 is the reduced rate of repeated pathology orders and other diagnostic procedures, due to the availability of trusted and dated information in the EHR; this is relevant both when GPs move

(GP turnover) and when patients take their record to the hospital or another health care facility.

Savings may be in terms of more appropriate investigations or lack of duplication of tests. Hammond<sup>131</sup> describes saving \$596 (39%) per patient annually in outpatients in 1990 despite clinicians spending 33% longer with patients. Tierney and others<sup>313</sup> at the Regenstreif Institute showed that using computer workstations to place orders reduced charges and hospital costs by 13% compared to a control group. Forty four percent of clinicians felt the system made their work faster. Prescribing support that leads to generic prescribing has been shown to lower prescribing costs by 12-30%<sup>18,133</sup> Tang believes that integrating decision support with clinician order systems can produce significant effects on quality and costs of care<sup>21</sup>.

***Large scale  
implementations***

Sometimes very large scale and expensive implementations are required before cost savings are possible. Introducing smart cards to 5 million Medicaid patients in 1997 in the State of California for administrative purposes cost \$34 million. The savings are expected to be in the order of \$27 million per year<sup>132</sup>.

A detailed list of cost-justifications for EHR systems in ambulatory care settings has been collated by Renner<sup>109</sup>; these include savings in space, assembling accounts received, greater patient throughput, malpractice premiums, improved billing practices, staff time and paper resources.

A Commonwealth Scientific and Industrial Research Organisation report in 1996<sup>130</sup> endorsed the economic basis for 'appropriate deployment' of IT based on Australian and United Kingdom foresight studies. On the basis of this report health authorities might expect to provide a more efficient service while containing costs through the ability to collect, analyse and share relevant data. Regardless, computers are now ubiquitous in health care facilities and the added cost of implementing an EHR is less overwhelming.

Finally, while concerned about the cost-justification of EHR systems, users, payers and government are concerned about the cost-justification of health care. The EHR will be required to gather this information as, at the end of the day, outcome data will be required<sup>134</sup>. The Institute of Medicine does not foresee this situation in the short term<sup>3:p85</sup>.

**• Implications for a national approach in Australia**

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- ◆ Cost savings can become the motivation for using EHRs which may lead to markedly increased profits<sup>135</sup> without consideration for quality of care.
  - ◆ Lowering prescribing costs seems less likely when prescribing systems are supported by the pharmaceutical industry, which is currently the norm in primary care in Australia.
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**4.7 IMPROVED MANAGEMENT AND UTILISATION OF HEALTH INFORMATION**

• *Evidence: T2.* EHRs allow powerful abstraction and reporting capabilities for population health, audit, research, and health service planning, as expressed by the NZHIS.<sup>86</sup>

*Once in electronic format, records can be reported upon automatically. Patient's treatments can be assigned to DRGs, statistical reports can be sent to the national collections, notifications (e.g. of births and deaths) can be sent to the Registrar-General and so on. Automatic audit reports can be prepared, for example, of caseloads, services provided, lengths of stay, costs of care and so on. Data can be quickly gathered for research studies and up to the minute reports generated. All the data required for administration and contract management can be derived from the medical records.*

#### **4.7.1 REPORTING ON WORK PATTERNS AND TRENDS**

The Netherlands has had a primary care information model developed through research and development at public expense and implemented in GP systems. General practitioners have taken an active role in this ongoing development since the early 1980s. Data from such systems can be used to support development of evidence based protocols<sup>87</sup>, generate risk prediction from routine data, or analyse outcomes and costs of programs or interventions<sup>136,87</sup>. Such information can then be utilised in the EHR systems from which it was derived.

Other examples of the uses of such data include generating a regional disease register<sup>137</sup>, undertaking a total audit of preventative procedures<sup>138</sup>, generating automatic reporting and notifications<sup>86</sup>.

#### **4.7.2 POPULATION AND MEDICAL RESEARCH**

Consumers can benefit directly and indirectly from research utilising the information in their records. They can also gain access to the results of quality of care audits, ensuring that their decision making is as well informed as possible. This will allow consumers to play an equal role in policy development.

Linking clinical databases can provide information of great value to policy and planning. Chamberlayne<sup>139</sup> describes the British Colombian experience of linking Hospital separations data, MSP payments, deaths, births, long term care and prescriptions for the elderly. He expects the beneficial use of data to increase as more databases 'are linked in'.

The USA National Committee on Vital and Health Statistics has stated:<sup>140</sup>

*The Committee recognizes the conflict between research and privacy, but requiring patient consent as a condition of researcher access is impractical and expensive. It would also most likely stop a significant amount of useful investigation. This is not in the health interests of the individual or the general population. Patient privacy interests are adequately protected by independent review of research protocols, the earliest possible removal of identifiers, prohibition against use of research records for actions against patients, and strict penalties against researchers who violate the rules.*

This may be the current state of affairs but is unlikely to be accepted by the wider community.

Population based approaches to health care undertaken in Dutch and British general practice are probably a strong driver for the acceptance of the EHR - as population based care is very difficult without some sort of computer assistance<sup>120</sup>.

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**• Implications for a national approach in Australia**

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- ◆ Unambiguous identification of individuals will aid population and medical research considerably through record linkage. This does not necessarily have to be on a national scale but will aid patient identification and add to the safety of automatic processing if it is so. It is worth noting that the CORBAMed group in the USA have proceeded with the abstract notion of domain identification where this is ensured within a certain domain only. Such limited scope of person identification may be more acceptable to consumers.
- ◆ Managers and organisations are the main beneficiaries when data required for other purposes are collected at the time of provision of clinical care. It is clear from the research evidence that efforts to overdo this or make it the focus of the system may well jeopardise the implementation.
- ◆ Van Bemmel<sup>120</sup> in his review of EHR systems in Europe points out that information in European health information systems is “*not crying out to be used for electronic data interchange, research or shared care*”. This is due largely to the problems that arise when the data is to be used for purposes other than direct patient care - for example the lack of common terminology or different context. He stresses the lessons learned from experience - particularly the

*need to develop structured patient records based on a clear conceptual model. If the data in the [EHRs] are not based on a conceptual model, and if the data in [EHRs] are not well structured, it will not be possible to use [EHR] data for different goals, nor will it be possible for such data to be exchanged between health care providers to support shared care.*

- ◆ Care providers need to be cognisant of the requirements for data to be shared over the entire health care domain and to support clinical research, policy making, assessment of quality of care, management and planning!
  - ◆ The regulations for protecting individuals in this setting must be explicit and are largely dealt with in the following section on difficulties.
- 

**4.7.3 SYSTEMATIC  
ASSESSMENT OF  
THE QUALITY OF  
CARE AND  
OUTCOMES**

- *Evidence: T3.* Managers and policy developers have a genuine need to ensure that the effort expended on EHRs is being returned in terms of outcomes. EHRs allow data collection during clinical use of the EHR - a great advantage over paper systems which require duplicate input.

Consumers will benefit from accurate performance information, for example through institution and provider bench marking. Information on outcomes can also be used to fine tune clinical guidelines, adapting them to the current context.

Policy makers and managers wish to accurately:

- forecast future trends;
- determine cost effectiveness;
- evaluate where most of the value for dollar lies; and

- assess the evidence base of interventions.

Governments also hope to ensure that large outlays of public money are producing the outcomes they hoped for and seek more complete and accurate information on the effectiveness and efficiency of health program expenditures. Further, evidence derived from EHRs can directly support development of population based health care policies<sup>87</sup>.

Clinicians in the USA have benefited through reductions of malpractice insurance premiums by as much as 5% as a result of improved coding and documentation and evidence supports substantial improvement in quality of care in some instances<sup>87,109</sup>. EHR systems certainly support continuous quality of care initiatives - this has been a key driver in the managed care environment.

But systems have to be able to provide the functions to gain benefit. In a systematic review in 1994 in the UK only 24% of systems could audit the clinical content of a patient review and only 52% could audit prescribing activity<sup>18</sup>. More than three quarters of the systems in use could not perform any statistical analysis and 76% had no graphical ability.

#### • **Implications for a national approach in Australia**

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- ◆ The National Committee for Quality Assurance has developed a framework for monitoring quality of care in an EHR environment. Such an approach may be required in Australia.
  - ◆ Accreditation of clinical systems, as practised in UK general practice, may be required to ensure that EHR systems can support the functionality to enable improved quality of care.
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## Part 5 Difficulties associated with Electronic Health Records



*For over a decade...writers have been advancing with almost religious fervour the urgent necessity for a comprehensive [electronic health] record. Influenced by visionary task forces and by rigorous informatics research data, an increasing number of faculty and administrators have rightly concluded that an effectively deployed [EH]R will help health care professionals provide better care to individual patients and to better comprehend the health care needs of populations. Now a number of commercial [EH]R systems have been introduced that promise to place into the hands of any institution with financial means systems once available at only a few of our most advanced medical centres...Facing the throngs of practitioners and patients anticipating the conferral of benefits, it seems almost heretical to ask the simple but vital question, **what if these systems do not work?** (Frisse<sup>141</sup>)*

EHR systems have proved to be very difficult to design and implement. Thus, there are a range of issues and difficulties that need to be addressed in detail before the introduction of a national approach to the EHR. Shortliffe<sup>142</sup> identifies four of these issues:

- the need for standardised clinical terminology;
- concerns about data privacy, confidentiality, and security;
- challenges of data entry by health professionals; and
- difficulties of integration of EHRs with other information resources in the health care setting.

While these issues are the most pressing for the moment, there are also other issues that demand attention. This part of the report examines moral, legal and ethical difficulties, problems of equity and access, implementation, technical and financial difficulties associated with the design and use of an EHR.

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### 5.1 MORAL, LEGAL AND ETHICAL DIFFICULTIES

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*The enhanced electronic capacity to collate, share, match and manipulate information generates risks as well as benefits<sup>42</sup>.*

There are major moral, legal and ethical issues in the development and implementation of EHRs which are of major concern to consumers and their advocates. Hence, much of the evidence in this section is drawn from documents<sup>23, 24, 25, 26, 27, 28, 29, 30, 31, 33,143</sup> produced or referenced by key consumer organisations.

### 5.1.1 CONSUMER CONCERNS ABOUT THE PRIVACY AND CONFIDENTIALITY OF EHRs

Medical records contain highly sensitive information about a person's health problems, family history, personal behaviour and habits. They may contain information about mental health, sexuality, drug use, genetic test results and HIV/AIDS and Hepatitis C status. Although the public has a high level of trust in current practices designed to protect the privacy of their medical records, new technologies and associated media attention have heightened consumer concern about privacy in the information age<sup>2</sup>. Consumers are concerned that information technology and EHRs will make their personal health information much more accessible, not only to health practitioners and hospitals, but also to a wide range of interested third parties, such as accreditation and standard setting agencies, government agencies, insurers, employers, laboratories, pharmaceutical companies, pharmaceutical benefit managers, pharmacies and researchers<sup>62,144</sup>. Furthermore, they fear that their personal health information may be used to discriminate against them in employment, insurance or housing decisions and may lead to particular consumers becoming the focus of unwanted attention.

#### *Examples of misuse*

The following examples of the misuse of medical records are not Australian, but they do illustrate the value of personal health information to third parties.

- A survey of the Fortune 500 companies found that 35% of the companies used health records in employment related decisions. Moreover, 1 in 10 of these companies did not tell their employees that this was company practice<sup>75</sup>.
- In the USA, a 1996 pilot study documented 206 cases of discrimination as a result of access to genetic information that resulted in a loss of employment and insurance cover or ineligibility for benefits<sup>145</sup>.
- Consumer health information was sold to pharmaceutical companies in the USA. Individuals became aware of the breach of confidentiality when, after having their prescriptions filled, they began receiving information in the mail promoting different medications, treatment and equipment<sup>35</sup>.
- The Icelandic government granted deCode Genetics Corporation an exclusive licence to establish a centralised databank of the medical records of the entire Icelandic population. deCode also has exclusive rights to commercial exploitation of the database for twelve years and has an arrangement with Swiss pharmaceutical company Hoffman-La Roche which gives the pharmaceutical company access to the database to research the genetic origins of twelve common diseases<sup>146</sup>. This has led to much debate and raised consumer concerns about potential threats to their privacy. The example aptly illustrates the potential economic value of personal health data to pharmaceutical companies<sup>58,147</sup>.

Other examples of misuse have occurred and have been thoughtfully documented<sup>144</sup>.

Fear of a potential breach of confidentiality regarding personal health information may also influence consumers' decisions regarding their health care.

- In the USA a 1997 national survey found that 63% of more than 1000 people stated that they would not allow genetic testing for diseases if employers or insurers could get access to the results. Eighty five percent felt that employers should be prohibited from obtaining information about an individual's genetic conditions, risks and dispositions<sup>145</sup>. "As knowledge grows about the genetic

basis of disease, so too does the potential for discrimination and stigmatization based on genetic information"<sup>148</sup>.

- One third of high risk women invited to participate in a breast cancer study refused to because they feared a loss of privacy or discrimination<sup>145</sup>.

Consumers' concerns about privacy and confidentiality can only be addressed by the explicit determining of the extent of the individual's control over their own EHR in regard to:

- control of access to the record;
- control of access to specific information held in the record;
- control of processing of the record;
- control of movement of the record;
- control of erasing the record;
- the degree of automatic notification of access to, processing or movement of their EHR.

#### **5.1.2 LEGISLATIVE APPROACHES TO PRIVACY AND DATA COLLECTION**

There is not a uniform approach to privacy protection within Australia - different standards and individual rights apply in different situations<sup>152</sup>. The ACT is the only state or territory which has legislation covering the handling of personal information in both the public and private sectors. New South Wales, the Northern Territory, South Australia and Victoria have developed, or are in the process of developing, codes addressing the privacy of health information in the public sector. In addition, various professional groups are developing voluntary codes of practice on patients' access to medical records, as for example the Royal College of General Practitioners' Code of Practice for the Management of Health Information in General Practice.

The *Draft National Health Information Standards Plan for Australia Action Paper No 1*<sup>150</sup> identifies the development of nationally consistent data protection legislation as a key objective. Similarly, *Health Online*<sup>2:p12</sup> notes:

*...trust in privacy and confidentiality of the sensitive information that patients share with their practitioner is fundamental to receiving appropriate care.*

And recommends:

*Acceptable legal and privacy framework to be in place to ensure such information can be transferred to authorised users for approved purposes in a secure manner.*

In the USA the need for federal legislation is also well recognised. *Promoting Health and Protecting Privacy: a Primer*<sup>62</sup> states that national legislation is important to ensure uniform standards for the use and disclosure of health information. Similarly, Tang<sup>149</sup> concludes:

*Only federal legislation can provide comprehensive protection for all uses and disclosures of individually identifiable health information... We also believe that federal health information standards must pre-empt the patchwork of inconsistent state*



*requirements if they are to provide real assurances of privacy to individuals at a time when health care is increasingly an interstate exercise.*

In 1998 the Australian government announced it would introduce light touch legislation to support self regulated privacy protection in the private sector with the *National Principles for the Fair Handling of Personal Information*<sup>151</sup> underpinning the legislation. However, it has been argued that specific legislation relating to health information needs to be developed and a body established to oversee protection of privacy of health information<sup>153</sup>.

***Growing need to know***

Consumer advocates are concerned about the growing number of people seeking access to medical records for secondary purposes and they are also increasing concerned about record linkage. The Consumers' Health Forum of Australia recommends that the following three principles form the basis of privacy legislation:

- Use of informed consent must underlie the use and disclosure of consumers' personal health information;
- The Commonwealth Government must proceed with national privacy legislation that is capable of both protecting consumers' privacy and ensuring their right of access to their own personal health information;
- The Commonwealth and State and territory governments must co-operate in the development and implementation of nationally consistent standards to govern the use, linkage and disclosure of consumers personal health information.

The need for legislation is reinforced by international trends which indicate that there is an increasing number of demands being made by people not directly involved in health care for access to identified or semi-identifiable health information<sup>152</sup>. Moreover, it is important that Australian privacy standards meet international standards<sup>154,155,156</sup>. Lesser standards may be a barrier to the global exchange of health information. The 'light touch' approach to privacy in the private sector is not consistent with the EU's directive which is enforceable by law<sup>154</sup>.

**• Implications for a national approach in Australia**

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- ◆ Legislation is required to ensure that person health information does not get into anybody's hands without individual and truly informed consent. *Health Online*<sup>2:p12</sup> implies that additional federal legislation will be necessary to further protect the privacy of personal health information

*The Commonwealth is in the process of introducing legislation concerning the protection of personal information in the private sector...However additional legislative approaches will need to be considered as emerging technologies are used to communicate highly sensitive information across health and community settings to support integration and coordination of care and to make better policy and planning decisions.*

- ◆ It is essential that this proceeds.
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### 5.1.3 ACCESS TO AND OWNERSHIP OF EHRS

At present Australian consumers do not have a uniform right of access to their medical records. They have right of access to records in the public sector but they do not have the same right of access in the private sector, which includes the records of general practitioners and many hospitals<sup>42</sup>. Australia lags behind other countries in this regard and consumers in the UK (Access to Health Records Act 1990), New Zealand (Health Information Privacy Code 1993) and Canada (Common Law) have a uniform legal right of access to their medical records.

#### **National legislation**

A report by the Public Interest Advocacy Centre (PIAC) recommends that national legislation be introduced in Australia to ensure a uniform approach to patient access to their medical records<sup>157</sup>. The importance of access to consumers is also acknowledged in *Health Online*<sup>2:p19</sup>:

*The issue of access to own their own health care records is also of critical concern to consumers.*

Consumer support for right of access is estimated to be between 75 and 90% and consumer advocates draw attention to the importance of access if consumers are to make informed decisions regarding access to their medical records by others:

*Effective notification and truly informed consent require that individuals know and understand the contents of the record.*<sup>42</sup>.

*Consumers cannot be expected to be confident about the possible consequences of allowing their personal information to be used for research purposes when they do not have access to the information themselves*<sup>24</sup>.

Only the ACT has legislation which gives consumers a generic right of access to private sector clinical records. The ACT *Health Records (Privacy and Access) Act 1997* covers all health records, in any media, held by any health service provider. The act has led to some changes in procedures at the three ACT hospitals<sup>17</sup>. It has also led to a small increase in consumer requests for access to their records and consequently to a slightly increased workload associated with photocopying records. However:

*Overall, the staff of the hospitals welcome the new legislation, which will enable the public to feel confident about the procedures in place to protect their information, and to enable access to their documentation*<sup>17</sup>.

#### **Consumer access**

A recent report by the NSW Health Council<sup>158</sup> highlights consumer problems with access in NSW:

*Consumers have little or no access to records, either in hospitals or through their GPs. Also, there is currently no mandatory requirement for a GP to release a patient's health record when the patient exercises their right to change providers, or when GPs move on. This is particularly important in rural communities, when the turnover of GPs tends to be higher than in metropolitan communities.*

Although it has been argued that access will lead to increased litigation, this is not supported by the *Interim Report of the Review of Professional Indemnity Arrangements for*

*Health Care Professionals* (1994). The report states that there has been no increase in litigation in NSW and Victoria as a result of consumers gaining right of access to their private hospital records under Freedom of Information legislation<sup>143</sup>. Moreover, the report suggests that access to medical records

*establishes more open and equal doctor/patient relationships, enhances informed consent, ensures continuity of care across various providers and gives consumers greater control over their own health.*

### **Ownership**

Ownership of paper based medical records has resided with medical practitioners (or their employees) who have had the right to decide whether or not to show a record to a person when requested to. The *Breen v Williams* High Court case confirmed this position and ruled that under common law the patient concerned had no right of access to her medical records. However, the ownership of EHRs is a complex issue, since electronic data can be copied very simply and the copy is indistinguishable from the original. Consumers, health care professionals, managers and third parties are all likely to experience difficulty when there is a dispute - particularly as ownership may vary from record to record!<sup>1</sup> Such ambiguity is likely to lead to legal action which will not necessarily resolve the situation. While each party might see advantage in resolving this difficulty, it is unlikely that the outcome will be satisfactory to all the others.

While copyright would normally reside with the originator of the EHR entry, a health care professional with a duty of care towards a particular consumer will need to be able to access a copy of the person's EHR without the explicit consent of the clinician who holds copyright.

#### **• Implications for a national approach in Australia**

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- ◆ Consumer access to their EHR is a definite requirement for EHR systems. Consumers need to understand the contents of the EHR - they need to ensure that it makes sense to them. For this reason they will need to be involved in designing a common interface or one that is tailored to their needs. The extent of consumer control over the processing of a record is also an issue that needs to be resolved.
  - ◆ A national approach to the ownership of EHRs, accepting that the ownership is ambiguous, is probably worthwhile to prevent the waste of resources. Hand-held or patient controlled EHRs, consisting of copies of encounters recorded by different health care professionals, may also resolve this situation without the need for legislation.
  - ◆ Whatever the final position on ownership, it is clear that consumers want control over access to their health information.
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#### **5.1.4 DEFINITION OF THE LEGAL MEDICAL RECORD**

As described in Section 3.1.2, "The 'boundary' of the EHR," on page 9, there is a need to define the boundary of the EHR. This can be quite straightforward in an environment such as that proposed by GEHR<sup>6</sup> but highly ambiguous in a hospital environment where there are many disparate systems and paper records to be considered. Okamoto has recognised this problem and proposed a location specific methodology for addressing this issue<sup>159</sup>. This clearly describes what information held at a particular location is part of the EHR and requires appropriate security and privacy procedures to be in place.

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1. *Health Services for Men v D'Souza*, NSW Supreme Court

It also determines the responsibility of health professionals and their duties with regard to the EHR. With the 'virtual health record'<sup>160</sup> this is problematic.

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• **Implications for a national approach in Australia**

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- ◆ Where a 'federation' model of health records (a virtual health record) has been implemented a clear process is required at each location to define what constitutes the EHR in that environment. This is not trivial.
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**5.1.5 LEGAL  
ACCEPTANCE OF  
ELECTRONIC  
TRANSACTIONS**

The Electronic Transactions Bill, 1999, has paved the way for health care to work in a paperless environment. The legal acceptability of health records in Australia is ambiguous but has been described from a health professional's perspective<sup>161</sup>. Although EHR systems are established in some medical centres in Japan, health care organisations are required by law to keep paper records<sup>162</sup>. Similarly, in the UK paper records are required by law, although approximately 10% of general practices have been paperless for many years. Computerised records in the UK are certainly admissible in court although the record is required to be maintained on proper hardware, the records must be contemporaneous and there should be a full audit trail of additions and deletions. However, implementation of true audit trails in EHR systems around the world are unusual and no certification process is usually involved<sup>163</sup>.

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• **Implications for a national approach in Australia**

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- ◆ A national approach to legal recognition is essential with clear guidelines and processes for implementing legally acceptable audit trails.
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**5.1.6 BALANCING  
ACCESS AND  
SECURITY NEEDS**

While the EHR has the potential to increase the amount and quality of information available to researchers and other interested parties, and subsequently to improve health care for consumers, it is not possible to achieve both the highest level of confidentiality and the broadest access to the record (whether on computer or paper). As confidentiality is very important, security of the EHR must be given high priority, as *Health Online*<sup>2:p19-20</sup> acknowledges:

*With increasing recognition of the individual and public benefits that can be gained through greater access to de-identified and aggregated clinical data for policy, planning and research purposes, has come acceptance that strict protocols and protective measures need to be in place to ensure that such activities can be agreed and undertaken in an environment of public trust...Electronic data transfer across the health sector also raises questions, not only about authorised access, but also about the certainty that such data is sent only to whom it is intended. Certification and registration for the purposes of electronic identification and authentication are crucial to this context.*

***Fair information  
principles***

Kluge<sup>164</sup> has generated a list of fair information principles:

1. *Openness*: the existence of an EHR data-bank, the kind of information it contains and the formally sanctioned use to which the data may be put must be a matter of public record, and reasonable efforts must be made to acquaint potential subjects with the existence and operation of the bank.

2. *Limitation of collection*: the collection of data that can be identifiably linked to the subject of the records should be ethically defensible in procedural terms and should be limited to those data only that are necessary to achieve the legitimate aims of the bank.
3. *Limitation of disclosure*: data that can be identifiably linked to the subject of the record should not be disclosed externally except with formal consent of that subject or a duly empowered legal authority acting in due process of law.
4. *Limitation of use*: data that can be identifiably linked to the subject of a record may be used only for the duly empowered legitimate purposes of the data-bank.
5. *Security*: the data collected about a specific subject should be protected by all reasonable appropriate measures against loss, unauthorized access, destruction, use, modification or disclosure.
6. *Access*: the subject of an electronic record must have the right of access to the record and the right to correction of that record with respect to its accuracy, completeness and relevance.

These principles are generic - and aim to place firm limits on what information is collected, for what purposes it is used and for how long it is retained. Security and access are also mentioned. In response to the UK NHS aiming to establish a private health network, Anderson has developed security policy principles for the British Medical Association (see Table 3, below) which aim to clearly describe a process for effecting privacy in a health care setting. Experience with implementing Anderson's principles is growing and the implications for practical implementation have been described<sup>165</sup>.

Anderson's principles have also been criticised by Rigby<sup>108</sup> (see page 32) who proposes a more consumer oriented approach.

**TABLE 3.** Anderson's security principles<sup>166:p247</sup>.

**1. Access control**

Each identifiable clinical record shall be marked with an access control list naming the people or groups of people who may read it and append data to it. The system shall prevent anyone not on the access control list from accessing it in any way.

**2. Record opening**

A clinician may open a record with herself and the patient on the access control list. Where a patient is referred, the clinician may access the record with herself, the patient and the referring clinician(s) on the access control list.

**3. Control**

One of the clinicians on the access control list must be marked as being responsible. Only she may alter the access control list and she may only add other health care professionals to it.

**4. Consent and notification**

The responsible clinician must notify the patient of the names on his record's access control list when it is opened, of all subsequent additions, and whenever responsibility is transferred. His consent must also be obtained, except in an emergency or in the case of statutory exemptions.

**5. Persistence**

No-one shall have the ability to delete clinical information until the appropriate time period has expired.

**TABLE 3.** Anderson's security principles<sup>166:p247</sup>.**6. Attribution**

All access to clinical records shall be marked on the record with the subjects name as well as the date and time. An audit trail must also be kept of all deletions.

**7. Information flow**

Information derived from record A may be appended to record B if and only if B's access control list is contained in A's.

**8. Aggregation control**

There shall be effective measures to prevent the aggregation of personal health information. In particular, patients must receive special notification if any person whom it is proposed to add to their access control list already has access to personal health information on a large number of people.

**9. Trusted computing base**

Computer systems that handle personal health information shall have a subsystem that enforces the above principles in an effective way. Its effectiveness shall be subject to evaluation by independent experts

Alternative approaches have been formulated. The aim of developing a 'need-to-know' access control mechanism has been the subject of a number of research projects. Morger<sup>167</sup> describes their work based on a work-flow model granting access during procedures to clinicians involved and retracting it following this process. Such developments are complex and difficult to implement in a generic form.

#### • Implications for a national approach in Australia

- ◆ Balancing access and security is difficult. As confidentiality is of the greatest importance, and all means of access are a threat to that confidentiality, all technologies that offer access to the EHR must be offered in terms of an added risk to privacy<sup>65</sup>. Only methods that offer far greater access with a small trade off on confidentiality are likely to be of interest to consumers.
- ◆ Control over access to parts of the record, even specific information, is considered important by many. This has been investigated by Jones who has demonstrated that neither clinicians nor patients behave consistently<sup>4</sup>. Others have raised issues of safety (e.g. referral or emergency treatment) and even questioned if it is possible (e.g. hiding HIV disease) to work with a record which is only partly available<sup>6</sup>. Implementation trials will probably be required to assess the full implications.
- ◆ Guidance on security principles implementation such as those proposed by Anderson and PCASSO are required<sup>165</sup>.

#### 5.1.7 CONTROL OF PROCESSING OF INFORMATION

Automatic processing of personal health information poses grave risks to the data subject. The EU's (Europe Union) Data Protection Directive which took effect in October 1998 protects the transfer of information to any country that lacks adequate levels of protection, including the USA. The EU's Protection Directive<sup>156</sup> prohibits data processing unless:

- the data subject has given explicit consent;
- the data subject is physically or legally unable to give consent but processing is required to protect his vital interests;
- the data subject has made the data public;

Health data is a special case and the benefit of processing for the good of the individual or the public good is acknowledged. For this reason there is a specific clause in the EC directive to allow “processing of the data when required for the purpose of preventative medicine, medical diagnosis, the provision of care or treatment or the management of health care services provided that those data are processed by a health professional subject, under national law or rules established by national competent bodies, to the obligation of secrecy”. Anderson<sup>166</sup> proposes that consent for this should be explicit, notified and recorded.

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**• Implications for a national approach in Australia**

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- ◆ Consumers who wish to have control over automatic processing of their personal health information may range from not agreeing to automatic contacts for preventative procedures to allowing all research agencies access for research purposes. Some consumers may wish to control each individual process very specifically.
  - ◆ Particular groups of consumers may have their own requirements concerning the collection and processing of their personal health information. The New South Wales Aboriginal Health Information Guidelines<sup>168</sup> state that consent should be obtained from Aboriginal communities or Aboriginal Community controlled Health Services for the collection and use of health related community information if Aboriginality is a key determinant, if data collection is explicitly directed at Aboriginal peoples; if Aboriginal peoples, as a group are to be examined in the results; if the information has an impact on one or more Aboriginal communities; and lastly, if Aboriginal health funds are a source of funding.
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**5.1.8 ACCURACY OF  
DATA IN THE EHR**

Errant data can be added to the EHR and then be used during an automatic process. This is potentially dangerous and, to a large extent, preventable. At the point of data entry there is an opportunity for the application to validate data input to some extent and offer the user the chance to change it. Such validation procedures are required for accreditation in UK general practice.

With interest in the EHR, studies have investigated the completeness and accuracy of data in Scottish GP systems<sup>169</sup> and in some detail in UK general practices<sup>170,171</sup>. Accuracy of prescription data<sup>172</sup> has also been described. These provide baselines but knowledge of data accuracy in EHRs is weak and further research is required<sup>173</sup>. The findings raise concerns that routinely collected information may not be sufficiently complete or accurate for outcomes analysis<sup>174,291</sup>.

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**• Implications for a national approach in Australia**

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- ◆ Minimal standards of completeness and accuracy of EHR data must be established for safe automatic processing, including aggregation of data. For example, decision support when prescribing is not safe

without all current medications and previous adverse reactions to therapy being recorded in the EHR.

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## **5.2 DIFFICULTIES OF ACCESS AND EQUITY**

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The Australian population is diverse and some people may experience particular difficulties with the introduction and implementation of the EHR<sup>175</sup>. Rural and remote communities, indigenous Australians, the aged, non English speaking people, mentally ill and illiterate people are already in a position of disadvantage when it comes to health care and may also face difficulties when EHRs are implemented<sup>175,61</sup>. As Tang<sup>21</sup> suggests:

*To the extent that healthcare becomes dependent on access to computer networks, however, policymakers need to pay special attention to the needs of the medically underserved population to ensure that lack of network access does not further impede their access to care.*

Both women and older people, who are high users of the health service, are, at present, less likely to use the internet than young men. In November 1999, according to data from the Australia Bureau of Statistics:

- People aged 55 and over were the least likely to have internet access (16%), while 73% of people aged 18-24 were likely to have internet access<sup>13</sup>.
- Older people are also less likely to use electronic banking<sup>13</sup>.

### **Rural communications infrastructure**

Communications infrastructure in rural and remote areas may mean that access to EHRs is more difficult for people living in these areas. In November 1999 17% of rural households had access to the internet compared to 26% of capital city households. Indigenous people are also likely to have restricted access, since many of them live in remote settings without communications infrastructure.

It is very likely that other groups who are at high risk for health problems, such as people who are unemployed, chronically ill or disabled, with substance abuse, or recent immigrants may face difficulties in accessing their EHRs.

Not all consumers find it easy or desirable to adapt to the next generation of information services<sup>2</sup>. Even those with access to the internet will vary greatly in their ability to make informed choices about their health care - a problem that may be exacerbated by the increasing amount of inconsistent and unfiltered health information available to



them on the internet. The table below illustrates some of the potential pitfalls for health consumers concerning the internet.

**TABLE 4.** Barriers, in *The Future of the Internet in Health Care*<sup>34</sup>

Barriers from a consumer perspective	
Security	<ul style="list-style-type: none"> <li>• Concern about privacy</li> </ul>
Characteristics of the internet	<ul style="list-style-type: none"> <li>• Instability and hype</li> <li>• Browser technology is weak</li> <li>• Search engines can't see dynamic web pages</li> <li>• Slow access in most homes</li> </ul>
Mixed quality of information on the internet	<ul style="list-style-type: none"> <li>• Anonymous, undated, minimum effort to publish, no regulation</li> </ul>
Physician ambivalence	<ul style="list-style-type: none"> <li>• Medical culture is conservative</li> <li>• May be threatened by informed patient</li> </ul>
Disarray of health care information systems	<ul style="list-style-type: none"> <li>• Not ready for consumer interaction in real time</li> </ul>
Too many standards	<ul style="list-style-type: none"> <li>• Messaging HL7 is widely used but not universally - imperfect in many areas</li> <li>• SNOMED is proprietary and not complete</li> <li>• Parochial and vertically differentiated standards will inhibit e-commerce in health</li> </ul>

The varied social and cultural backgrounds of Australian health consumers mean that they also seek information and help from a wide range of complementary health practitioners. In one year in Australia, almost half of a representative sample of consumers had used at least one non medical complementary remedy and at least one in five had attended a non medically trained complementary therapist<sup>176</sup>. Moreover, “doctors underestimate their patients’ use of these therapies, which may contribute to compliance and medication interaction problems”. A uniform approach to the recording of personal health information in relation to complementary health care is necessary and at present the role of the EHR is uncertain in this context.

#### • Implications for a national approach in Australia

- ◆ The positive impact of introducing EHRs on health status in situations where there is deprivation is likely to be greater. There are two factors likely to contribute to this - the increased prevalence of health problems and the decreased likelihood that patients will present to health care providers specifically to address these problems. A national approach must ensure adequate implementation in populations known to be at risk.
- ◆ Consumers who do not take up online access to their health information should not be disadvantaged. Possible approaches to address this

potential difficulty include assistance to seek information in settings such as primary health care and access in other forms such as phone-in advice to trusted parties who have access to their EHRs or providing written information based on the contents of their EHRs.

- ◆ It is important that health providers do not to rely solely on computers as communicative and information tools but that they provide multiple modes of accessing many different sources of information<sup>175</sup>.
  - ◆ We are a geographically large nation and we have a population that is spread throughout - sometimes very thinly! Remote people also want access to the EHR and all that it promises.
  - ◆ A national approach to electronic health records must be culturally inclusive and be of benefit to all citizens. People without personal access to the internet and their health records online must have private and affordable access through public means.
  - ◆ Indigenous community controlled health services must be the brokers of the implementation of EHRs in their community. The choices may differ but must be incorporated into a national approach.
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### **5.3 IMPLEMENTATION DIFFICULTIES**

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One major difficulty in the implementation of EHRs is that the control and design of hospital information systems has been in the hands of the managers and financiers of health departments. Rector and colleagues<sup>177</sup> state:

*We maintain that the principal purpose of the medical record is to support individual patient care. The design of many existing electronic medical records derives, implicitly or explicitly, from support for the use of aggregated data for research, audit, finance, or planning. We maintain that such designs are inappropriate for a record for clinical use and, ultimately, inadequate.*

The UK Audit Commission Report (1996)<sup>77</sup> stated that despite spending of UK£56 million, computers in health care have failed to deliver expected cost savings. To add to this rather pessimistic view there are well documented horror stories<sup>178</sup> and long list of problems<sup>179</sup> derived from real experience<sup>181</sup>.

#### **5.3.1 IMPLEMENTING CLINICAL SYSTEMS**

A great deal has been learned about implementation of clinical computing systems over the past three decades. Frohwerk<sup>112</sup> has described in some detail the issues for operations staff when approaching the implementation of an EHR system. Although systems may not deliver all they promise because of technical difficulties, most implementation issues are human and can be avoided. Atkinson<sup>182</sup> challenges this view, somewhat, with his metaphor of growing, not building, an EHR system. He suggests an evolutionary process is required leading to a 'symbiotic' relationship between the information system and the rest of an organisation.

Further insight may can be gained from a major Canadian project involving the implementation of an EHR system in 4 hospitals between the late 1980s and 1996. Although implemented in 2 stages over almost 10 years and costing US\$50 million, it was withdrawn due to boycotts of medical and nursing staff<sup>183</sup>.

*The project was initially sold as facilitating medical work, improving coordination between nursing and medical activities, improving quality of care, and cutting costs. It resulted in information overload and standardisation, task load increase, work organisation rigidification, and expert autonomy negation.*

A summary of intended and observed effects of the proposed process innovations are described in Table 5 below.

**TABLE 5.** Intended and observed effects associated with process innovations (from Sicotte<sup>185</sup>)

Process innovation mechanisms	Intended effects	Observed effects
Process automation (direct data entry by nurses and electronic transformation and communication)	<ul style="list-style-type: none"> <li>Decreased clerical work load</li> <li>Elimination of time lag</li> <li>decrease in costs linked to clerical work</li> </ul>	<ul style="list-style-type: none"> <li>Increase in nursing clerical tasks</li> <li>Higher formalisation of data collection</li> <li>Less flexibility in work organisation</li> </ul>
Analytical improvement	<ul style="list-style-type: none"> <li>Improved analytic abilities</li> </ul>	<ul style="list-style-type: none"> <li>High formalisation and standardisation of nursing cognitive process</li> <li>Nurse deskilling</li> <li>Information overload</li> <li>Less flexibility in work organisation</li> </ul>
Process sequence	<ul style="list-style-type: none"> <li>Acceleration of completion of the collection of nursing data</li> </ul>	<ul style="list-style-type: none"> <li>Elimination of existing parallel processes - care delivery and patient assessment</li> <li>Less flexibility in work organisation</li> </ul>
Tracking capability	<ul style="list-style-type: none"> <li>Tracking in real time of information processes</li> </ul>	<ul style="list-style-type: none"> <li>Automation of people control</li> </ul>
De-localisation (Elimination of geographical boundaries)	<ul style="list-style-type: none"> <li>Consultation of patient files at a distance</li> </ul>	<ul style="list-style-type: none"> <li>Inoperative for nursing work</li> <li>Less flexibility in work organisation because of localisation constraints - bedside terminals</li> </ul>
Integrative capacity	<ul style="list-style-type: none"> <li>Horizontal care supervision and coordination across various functions and departments</li> </ul>	<ul style="list-style-type: none"> <li>Inoperative</li> </ul>
Information capability	<ul style="list-style-type: none"> <li>Staff planning and allocation</li> </ul>	<ul style="list-style-type: none"> <li>Increased control of staff</li> <li>Less flexibility in work organisation</li> <li>Increase in nursing task</li> </ul>
Intellectual capability	<ul style="list-style-type: none"> <li>Build knowledge-base</li> </ul>	<ul style="list-style-type: none"> <li>Inoperative</li> </ul>

Based on general information technology implementation experience Frisse<sup>141</sup> concludes that implementations that are revolutionary may promise the maximum gain but, even in well financed sectors (such as air-traffic control and ambulance coordination), can prove to be catastrophic disasters. He proposes an ‘institutional bill of rights’:

- do no harm - confidentiality must come before access;
- distinguish between the benefits of output (usually *under*-estimated) and the burden of input (usually *over*-estimated);
- emphasise training;
- develop objective measures of overall performance and reliability, including conditions under which the ‘plug will be pulled’;
- measure expense in terms of total cost of ownership;
- seek alternatives - but compare apples with apples;
- do not ascribe all benefits of organisational change to the EHR system;
- plan for the worst and hope for the best;
- estimate potential risk honestly; and
- share risk fairly.

The last principle seems particularly important in Australia where there are a number of stakeholders with very different exposures to risk.

***Importing  
systems from  
elsewhere***

Hannan<sup>184</sup> has described in some detail the difficulties of implementing a clinical system designed in the USA in an Australian setting - only some of the modules could be implemented and new modules had to be developed locally. The lessons from this major implementation were:

- implementation needs to be incremental;
- EHR systems significantly alter work practices;
- it is preferable to start with a sound system that has been evaluated in its development;
- it took almost 10 years to implement an effective system;
- involvement of users is essential;
- the team must have a leader who is clinically orientated, understands the domain, is available to users and be able to take tough decisions; and
- projects must have an ongoing evaluation component to justify costs.

The ‘people problems’ are recognised as more important than technical problems. Some investigators have concentrated on these aspects of implementation. Adyin<sup>115</sup> evaluated an implementation in ambulatory care and concluded:

- most physicians anticipate enough benefits to be willing to use the system;
- computers must be accessible, easy to log into, and provide for physician movement and interrupted sessions;
- many physicians are concerned about losing eye contact with patients;
- it is unrealistic to expect even good typists to enter their own long notes;
- staged implementation, with order entry introduced first, may help physicians adapt gradually; and

- training should include protected time for instructional sessions for physicians, simulated patient encounters to help physicians adapt their practice patterns, and tutors available to answer questions in the clinical setting.

Although it is common in hospital settings in the USA to use dictation and transcription, it is worth noting that in primary care settings it has been found that health professionals prefer to enter data directly<sup>186</sup>.

#### ***Paper paradox***

Unexpected results sometimes occur when EHR systems are implemented - even those of high quality. The experiences of the Beth Israel Deaconess Medical Centre have been published and have shown a 'paper-paradox': the system aimed to eliminate paper but has lead to an increase in paper usage<sup>188</sup>. In this system clinicians work with printed forms of the record and data entry sheets, using transcription clerks to enter the data into the system. As a result, cost savings have been only 20% of those anticipated.

Whether the approach is evolutionary or revolutionary, at some point an evolutionary approach will be required. Many of the older systems in the USA are still evolving after many years as the institutions have too much data held within them to alter there approach at this stage. As a result, legacy systems will always need to be catered for in any large scale approach to the EHR.

#### **• Implications for a national approach in Australia**

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- ◆ Best practice for implementing EHR systems will need to develop and be supported and documented. Clinicians will need to be intimately involved in that process, with planners and managers. The consumer will want to be there too!
  - ◆ Leaders will spend more money developing solutions and will carry more risk of their approach 'becoming an island' through technological developments in new directions. A national approach needs to ensure fair exposure to risk in the development and implementation of EHR systems.
  - ◆ Legacy systems will continue to exist. Institutions will have systems that are not provided as total solutions that need to interact with other parts of these systems. Total solutions will need to communicate with systems at other sites. Proposals for future developments need to accept these two realities.
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#### **5.3.2 APPLICATION INTERFACE DIFFICULTIES**

Weiner's<sup>133</sup> comprehensive review of computer based order entry systems in use around the world demonstrated that clinicians spend more time (5.5 extra minutes per patient) entering orders on computers than on manual systems - though there are administrative gains in other areas. Despite these findings users were generally satisfied with the systems due to perceived benefits.

Health professionals use of different data entry mechanisms (when offered the choice) is quite varied and difficult to predict<sup>187</sup>. Generally, more sophisticated approaches have not yet met users expectations<sup>189</sup>. Voice recognition promises much in the future for long free entries but is of limited value due to its requirement to adapt to each user and the technical difficulty of natural language processing.

A review of clinical applications has shown that the layout is generally not intuitive for clinicians - designers are often tempted to embellish data with unnecessary colour or

icons<sup>107</sup>. It is clear that for the most part designers are programmers, not clinicians. This is not so often the case in primary care where many systems have their roots in a home grown system developed by a clinician programmer and may explain to some extent why systems have been more acceptable in that setting.

### 5.3.3 INFORMATION COMPLEXITY

*Making the impossible very difficult!* (openGALEN<sup>191</sup>)

The inherent complexity<sup>190</sup> of health related information has made the task of describing an EHR information model challenging, and hence retarded the implementation of standardised systems or components. This is borne out by experience on the GEHR project, the CEN EHR pre-standard work, and cost-benefit evidence published relating to the use of HL7 v2.x in Australia and in the US. GALEN<sup>191</sup>, a major European project to enable capture and classification of natural language in health care, has not delivered the hoped for results.

EHR information is complex due to having a number of levels of abstraction, as follows<sup>193</sup>:

- *Data*: all kinds of text, terms, multimedia, quantities, units, and more recently XML and interactive information. Systems of formalised terminology have in themselves been sources of major difficulty, although the successful use today of such systems points toward their ubiquitous use in some form in the future;
- *Basic clinical structures*: groupings of data into semantic structures corresponding to basic clinical concepts such as "blood pressure", "prescription" and so on;
- *Derived and synthesised clinical views*: higher-level grouping and linking to support "headings" (as in a paper record) as well as concepts such as "problem", "episode", "care plan", "care pathway", "current medication", "adverse reactions" and so on; and
- *Record management structures*: arrangement of clinical structures into containers such as "transaction" or "record-section", which would typically be the unit of storage, transmission, security etc.

The size of the clinical information space (roughly, the second level above) is enormous, as can be gauged by the size of some of the terms sets (e.g. SNOMED has more than 300,000 terms)<sup>192</sup>.

#### **Rapid evolution**

Not only is the complexity of clinical information greater than in many other domains, it changes all the time, as evidenced by the evolution both of care management precepts of "problem", "issue", and more recently "care pathway", and development in clinical concepts (e.g. The LOINC code system). The problem is the same as in other sectors: software built on today's ideas may be out of date tomorrow.

The challenge of complexity needs to be met by approaches in information modelling which take account of:

- The need to satisfy continual changes;
- Not obliging systems and consequently carers to adopt a fixed model of practising or recording information; and
- Being semantically powerful enough so as to be able to represent the types of concept mentioned above (i.e. not being a "lowest common denominator" solution which ultimately provides little value).

The comprehensiveness of the EHR is a key requirement<sup>9</sup> and is only possible if the solutions deal with the complexity issues.

It is worth noting that the needs of health care professionals may vary greatly<sup>194</sup>. Specialists often need to keep lengthy records. Some have highly specialised notations, drawings and other recordings. Highly specific systems have been built to cater for locations such as intensive care<sup>180</sup> or even to support care of patients with particular diseases<sup>195</sup>. The diversity will be even greater when 'alternative' practitioners or those from other 'medical cultures' use the same record!

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**• Implications for a national approach in Australia**

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- ◆ There is a limited understanding of the complexity of the information in clinical systems. Recent key work in HL7 (USAM 2, PRA), CORBAMed, the Synex Project's federated record system and GEHR (the Ocean Kernel) confirms this. A national approach needs to embrace these aspects of EHR development.
  - ◆ Specialised recording will need to be catered for in any national approach. Until the formal meaning of notations are available for automatic processing - it may not be safe to include these in the EHR, as key clinical information may not be accessible.
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**5.3.4 STANDARDS ARE REQUIRED FOR COMMUNICATION**

To enable the simplest sharing of data (not just text) requires standards. These are required in a minimal way for viewing a record from another site but are essential for any processing of the record (such as for decision support etc.)

Different standards are required at the different levels described above:

- *Data*: standardised vocabularies such as SNOMED-CT (merger of SNOMED and Read), ICD-10 AM and ICPC, image standards such as DICOM 3, signal standards (ECG), multimedia standards etc.;
- *Basic clinical structures*: standardised terms to label content such as LOINC, how to communicate this information in messages such as HL7 or through communication technologies such as CORBAMed, groupings of content into meaningful clinical concepts such as blood pressure, a prescription or an audiogram as partly covered by LOINC and more comprehensively in the GEHR archetype system;
- *Derived and synthesised clinical views*: more complex structures that have been developed over time by clinicians, now labelled by CEN and dealt with in GEHR and HL7 - PRA but probably remain in the clinicians' domain; and
- *Record management structures*: arrangement of clinical structures into sensible 'containers' (as proposed by GEHR and more recently by CEN and the HL7-PRA) to enable record management as required by clinicians and patients.

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**• Implications for a national approach in Australia**

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- ◆ The choice of standards is huge with more than 150 vocabularies in use today around the world, with merging of key players such as SNOMED and the UK Clinical Terms (Read). Alignment of HL7, CORBAMed and GEHR is beginning with a shared understanding of the move to more complex information models in clinical computing. A national approach will need to be cognisant of these developments.
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- ◆ The primary care coding jury will shortly announce which coding system is to be used in Australian general practice. Many systems have been considered; two home grown contenders, ICPC 2 plus and DOCLE are competing with international giants such as SNOMED-RT. ICD10 remains a possibility for problem lists which are disease based. ICPC 2 plus has its origins in prospective research in Australian general practice and is based on the internationally accepted classification of primary care (ICPC 2). Docle is the personal invention of an Australian GP and is used in the most widely used general practice software.
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### 5.3.5 PATIENT IDENTIFICATION

An agreed system of patient identification has been one of the principal technical impediments to sharing health records outside particular health care institutions. In most countries there are proposals for national schemes, and they have been implemented in the United Kingdom and New Zealand.

Technical approaches to patient identification without national agreement have been proposed. The primary example is the Open Management Group's (OMG) CORBAmEd "PIDS" (Patient IDentification Service) proposal, based on the use of id domains and id correlation to distinguish patients in the real world, rather than a theoretical algorithm or information structure. PIDS, like other OMG domain-specific interfaces, is defined in terms of IDL interfaces which can be implemented with CORBA or other technologies, thus enabling systems to interrogate each other according to the semantics of the interface.

The PIDS<sup>196</sup> takes into account a number of real world problems not dealt with by more theoretical approaches to identification, including:

- support interactive and message-driven (unattended) modes, independent of matching algorithm;
- supports identification in the face of highly incomplete identifying information;
- supports both manual and automated correlation of IDs and records associated with health care consumers that have received care in different settings; and
- will address the problems of correlating IDs among the ID domains of highly autonomous and frequently re-organising entities.

PIDS also addresses patient confidentiality by defining interfaces which can enforce any policy defined in terms of user identity, target person identity, ID domain, person traits requested and has already been implemented by Los Alamos National Laboratory TelemEd project.

The GEHR approach, utilising PIDS and sharing identity transactions, leaves a trail of person identifiers that will enable perfect record linkage where there has been communication between the two data sources. This approach would ensure that record linkage is only available when consumers have consented.

#### • Implications for a national approach in Australia

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- ◆ A national person identification number (PIN) would simplify systems issues to a great extent. It will require a national structure to maintain this system and reducing duplications etc. Travellers, and others who do not give identification details consistently, will con-



tinue to confound efforts to build a national database. Linking the number to billing seems a useful way to minimise the administrative overhead.

- ◆ Approaches of CORBAMed and GEHR may be required where national approaches are not politically feasible such as in the USA.
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### 5.3.6 SECURITY OF COMPUTER SYSTEMS

*No security can be achieved if everybody is hostile and all machines are faulty. (Pfizman)*

Security, according to the Oxford dictionary, is “safety against attack, impregnable, reliable, certain not to fail, in safe keeping, and firmly fastened”. All of these concepts are valid when considering the EHR. There is an evolving framework, both theoretical and legal, to ensure and maximise the security of information systems. Security of systems is generally classified as follows:

- Confidentiality, ensuring people can only access authorised information;
- Integrity, ensuring systems do what is expected of them; and
- Availability, ensuring that systems are available when required.

Security is not just a technical issue, but includes physical security, procedural security and staffing security<sup>197</sup>. Security is a major concern for all involved in the implementation of information technology (IT), particularly those in banking and health care.

Asaro<sup>198</sup> has analysed scenarios of possible security breaches and developed a taxonomy for determining the information required to monitor security closely. Determining factors such as patient and provider factors, and session characteristics form the basis of this approach.

#### **Physical threats**

Stealing the computer is a threat, particularly in primary care. So is unauthorised access when systems need to be repaired or upgraded. The duties of the controllers to maintain physical security of the system must be agreed. There is wide acceptance of such requirements and generally system providers are interested in meeting such standards<sup>199</sup>. Consumer acceptance is unlikely without confidence that this is the case and governments are under pressure to take a national approach to protection of health information<sup>200,201</sup>

Parker<sup>202</sup> describes six functions of information security:

- Avoid the loss of information by providing a barrier between potential threats and the data;
- Deter information loss by anticipating accidental or intentional unauthorised behaviour;
- Prevent unauthorised access through system configuration;
- Detect any loss of information to minimise adverse impacts;
- Recover with a minimum of damage after a loss has occurred; and
- Correct system vulnerabilities to prevent the same loss from happening again.

There is a special case in the environment of consumer held records - that is the right of deletion of parts of or the complete health record. It is clear that consumers will only hold their own record if it is in their interests. They may choose to delete parts of the record if they have control, though the duty of the health professional to hold records of

their own is more important in this context. Electronic health records make dealing with these issues far more straightforward than with paper.

### 5.3.7 SECURITY OF TRANSFER OF EHRS

Transferring EHRs requires a different approach from the paper record. Machinery to intercept transmission data can be bought for as little as \$200<sup>203</sup>. Issues are somewhat similar to those associated with faxing records. However, transfer of an EHR is different from a paper record. An identical copy of the record, indistinguishable from the original, can be created and sent. The record may be sent to many sites simultaneously. Movement is an operation on the record, and has at least three attributes to describe it: type, extent and conformance - described in the table below.

**TABLE 6.** Analysis of transfer of EHRs

<b>Type</b>	Copy	Copying the original record and sending it to the new site
	Move	Copying the original and sending it to a new site, with destruction of the original. Destruction implies leaving it in an unrecoverable state. This would also apply to backups
<b>Extent</b>	Complete	The operation involves the entire original record
	Partial	The operation does not involve all of the original record
<b>Conformance</b>	Conformant	Transfer to a health care facility which adopts a standard of security and processing controls which are broadly the same
	Non-conformant	Transfer to a health care facility which adopts a standard of security and processing controls which are significantly less stringent or more accessible (or might be perceived to be by the patient) than the sender's health care facility

Transfer of the complete record is a particular event which warrants very careful attention as it may happen when an EHR source is closed or requires upgrading. Legal difficulties arise if a controller can move the EHR to another health care facility without strict rules on validating error free receipt, acknowledgement of the status of the record and agreement to hold the record in a suitable state for required lengths of time - particularly if regulations differ across state boundaries.

The transfer of the EHR may be to a health care facility which works to standards which are similar to that of the originator of the record, or to a health care facility which has differing standards. The latter poses a potential threat to the patient and clinician. Such transfers may be described as non-conformant and are more likely with international movements. The EC has made specific provision in its directive<sup>156</sup> to protect consumers from such movements of EHRs.

Patients may only be willing to seek medical care on the basis that there will be no flow of information between providers. For whatever reason they may not wish their GP to

know about all of their medical problems. The same applies to some information which the patient may wish to communicate to the GP, but not a referral specialist. To deny this right would be against the best interest of the patient and the public. Circumstances where the patient would not control the movement of the EHR would almost entirely fall into the category of reduced competence.

De Meyer and colleagues<sup>204</sup> have analysed requirements for EHR transfers which they consider must include:

- the originator of record (authenticity);
- evidence of the integrity of the record (complete, unchanged);
- the date and time submitted;
- the date and time delivered;
- the date and time receipted - within a non-repudiation framework; and
- validation of data subject.

Further, data must be secure during transmission and, as stated above, there must be a framework of non-repudiation - that is someone who receives the record cannot deny this in the future. The most promising approach to these problems are the public key infrastructures being developed as a generic solution to this problem across all sectors of the IT industry.

#### ***Transfer over the internet***

The use of the internet to transmit EHRs raises extra security concerns for both providers and consumers. A recent report, *The Future of the Internet in Health Care*<sup>34</sup> lists several of the key security issues:

- protecting servers and databases from unauthorised intrusion/modification;
- authenticating the identity of senders and recipients;
- protecting the integrity of the message itself;
- ensuring that senders cannot falsely deny they sent a given message;
- establishing audit trails; and
- ensuring the confidentiality of messages.

Confidentiality principles for web based record systems have been proposed by Rind and cover some further aspects of record transfer in an internet environment<sup>205</sup>. They have also proposed specific bases for ensuring authentication of patients in this new environment based on their experimental experience with the W3-EMR project<sup>65</sup>. The PCASSO project (<http://medicine.ucsd.edu/pcasso/>) funded by the Institute of Medicine (USA) has implemented many of these using simple floppy disk technology - although some clinician users have found logging on to the system too arduous.

#### **• Implications for a national approach in Australia**

- 
- ◆ A national and robust Public Key infrastructure as outlined in *Health Online*<sup>2</sup> is required to enable secure transfer of EHRs.
  - ◆ Security required for financial transactions over the internet are likely to be adequate to protect personal health information during transfer of EHRs. Given this situation, the main issue from a health perspective becomes the appropriateness of the EHR transfer<sup>65</sup>.

- ◆ The insurance of integrity of the EHR on transfer is extremely important, since subtle errors could creep in depending on the kinds of processing carried out at the receivers end at each transfer. This is a strong argument for a GEHR-style kernel component approach.
- 

### 5.3.8 ACCEPTANCE BY HEALTH CARE PROFESSIONALS

There is growing evidence of increasing acceptance by clinicians of information technology especially if patient care is seen to benefit. Bolton and colleagues showed that the belief amongst Australian general practitioners that “prescription writing is easier using a computer” jumped from 35% in 1994 to 52% in 1996. Further, the percentage disagreeing with the statement fell from 30% to 16% in the same period. The same group, however, were more likely to agree with the statement “If I were to computerise my practice, in order to maintain my income, I will probably need to work more than I do now”; 49% in 1994 and 62% in 1996<sup>206</sup>.

There is no doubt that a major barrier to uptake of EHR technologies is the preparedness of health care professionals to take on the role of computer operator. Reed Gardner, who has overseen the Salt Lake City implementation at LDS Hospital states that success is 80% dependent on people and only 20% on technology<sup>14</sup>. Research needs to describe best practice methods and cite clear evidence<sup>115</sup>.

An increase in the time spent with patients seems likely - although this may be due to providing more complete care. A systematic review of consultations in general practice revealed that the consultation is approximately 48-54 seconds longer when a computer is used - this seemed to get longer with time<sup>208</sup>. Most of this added time was due to computer tasks. Doctor initiated and ‘medical’ content of the consultations increased at the expense of a reduction in patient initiated and ‘social’ content<sup>44</sup>. Clinicians views have been surveyed and they say that they are not motivated to collect data that they consider to be non-essential<sup>18,209</sup>. However, the application user interface design is important<sup>212</sup> and can assist in achieving acceptable compromises.

Computer assistance can provide information in the consultation which increases difficulties for the clinician - such as with programs that predict risk of certain outcomes<sup>100</sup>.

#### *Involved in design*

Clinicians are increasingly aware that getting involved in the design and implementation of EHR systems is essential. “Lack of input by clinicians into the design of health information systems has been cited as a major factor in the failure of information technology in health services and has prompted many clinicians to become involved in such endeavours”<sup>210</sup>. To do so, they need a working knowledge of evaluation of clinical systems to take of responsible role<sup>210</sup>.

A number of comparative studies in Australia<sup>213,214</sup> have concluded that health professionals who do not use computers are not sufficiently aware of the benefits of computerisation to make an informed choice about computerisation. However, job design and management information science literature suggest that perceived usefulness of applications is the main predictor of subsequent use<sup>215</sup>. Dansky and colleagues have

reviewed the predictors of perceived usefulness and their findings are listed in Table 7 below.

**TABLE 7.** Predictors of perceived usefulness, Dansky et al. 1999<sup>215</sup>

Predictor	Positive correlation	Negative correlation
Individual characteristics		Computer anxiety (which is closely associated with age) Lack of computer experience
Patient care values	Supports underlying patient care values currently in place Health professional values scientific approach	Health professional sees health care as an art not a science Health professional sees relationship with patient as highly personal
Clinic conditions	Value administrative efficiency and see current practice as less than ideal	See current organisation as ideal
Organisational support	System responsive to the 'culture' of the organisation	Lack of training and skill required to use system

These factors need to be taken into account when assessing health professionals' views of clinical systems.

#### • Implications for a national approach in Australia

- ◆ If clinicians are to be involved in design and development of EHR systems then a number of clinicians, specifically those in leadership roles, require a working knowledge of evaluation issues in order that they can assess the strengths and weaknesses of evaluation studies.
- ◆ Clinicians require meaningful opportunities to "test-drive" and appraise fully functional systems as well as effective training in maximising the benefit from their computer system and information management<sup>14</sup>.
- ◆ The ISO group, led by Australia and with input from Europe, Asia and the Americas, are determining a common set of requirements which can be used as the repository of agreed features of EHRs. This will allow development of a requirements methodology for use in developing user interfaces, applications and systems, of which hospitals and other software development organisations can take advantage.
- ◆ Consideration of the GEHR archetype approach is warranted - an EHR architecture which has the feature of allowing clinical models to be added and amended 'post-hoc'.

#### 5.3.9 PROVISION OF EDUCATION AND TRAINING

It must be stressed that education and training is essential - for all users of EHR systems and for consumers <sup>216,217,218</sup>. Changing job specifications of health professionals to include this may be indicated as, for example, in one instance lack of familiarity by junior staff led to an increase in patient waiting time and staff workload<sup>105</sup>. Data quality

has been shown to be dependent on training<sup>219</sup>. The UK is addressing this need formally with a curriculum for IT training in General Practice<sup>220</sup>.

• **Implications for a national approach in Australia**

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- ◆ Undergraduate and ongoing postgraduate training and skill development in health informatics is important for the future success of design, implementation and evaluation of EHR systems.
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### 5.3.10 SAFE CLINICAL SUPPORT

The safety of clinical support systems relies on many variables - the correctness of the software system, the education of the user and the completeness and accuracy of patient data. In the vast majority of systems in use “the level of clinical data provided to physicians and their care providers is not adequate for the treatment of patients”<sup>105</sup>. Clinical decision support need to be tested and accredited.

• **Implications for a national approach in Australia**

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- ◆ Accreditation procedures may be required for clinical support in EHR systems.
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## 5.4 TECHNICAL DIFFICULTIES

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The technical difficulties when installing and upgrading an EHR system can be overwhelming and account for a significant proportion of implementation difficulties. Implementation in many settings is highly complex. Consider the situation in the USA. Many HIS systems have been built using mainframe technology and are not open systems. They are service oriented dealing with administration, admission and discharge details and results reporting. Data entry, particularly in the USA, is not done by the clinician requiring print-outs and transcription of entries. Often there are conglomerations of laboratory, radiology and pharmacy systems as well as the administrative system. Billing is usually done by a separate system<sup>14</sup>. Technical difficulties are bound to arise!

Multi-site federated web based EHRs<sup>85,221,222,223</sup> have to overcome many of these difficulties but usually do so when there is a single controlling agency. Extensions of industry standards, such as SQL<sup>224</sup>, or other innovations<sup>225</sup> may be required to deliver information from EHR systems to clinicians. Computing power generally doubles in performance and halves in cost about every 2 years<sup>21:p3</sup>, but even with these major advances the true EHR has been difficult to achieve.

Technical barriers remain to the transfer of EHRs<sup>83</sup> even when sites are using the same system<sup>218</sup>. The ‘textBase’ project, which aimed to allow transfer of health records from one system to another in UK general practice, has demonstrated the complexity of the problem associated with no core record architecture<sup>82</sup>. Middleware, such as the GEHR Ocean kernel, working between the clinical application and the data storage, is considered inevitable but has a significant design overhead<sup>227</sup>.

Safety issues may arise when data is transferred to a new system that is not compatible with the older system. Ellis and Kidd<sup>218</sup> describe a data transfer that resulted in nearly 90% of patients having an active problem of Asthma. In fact, in the previous system negative findings were recorded - but this was not catered for in the newer system. The

field identifying that the patient *did not* have asthma was lost, thus leading to all entries of asthma in the database being recorded as problems.

Technical difficulties with aiding health professionals to enter data remain despite windows and other graphical user interfaces<sup>228,212</sup>.

*Entry of data into electronic patient records is a critical function that is fraught with challenges, mainly because it involves translation not only of facts, but also of knowledge and intuition from the mind of a trained provider into a machine that accommodates only zeros and ones. (Bradley<sup>230</sup>)*

**Interface**

Windowing environments with icons and images have not been proved to be the best solution on formal evaluation. Industrial engineering studies at the Regenstrief Institute have monitored clinician eye movement and learned that packing as much information into the screen 'real estate' as possible is the key to maximum usefulness<sup>110</sup>. Health professions, particularly junior staff who move between health facilities, find the lack of standards in interfaces difficult - standards initiatives such as CCOW aim to address this. Clearly there are many interface issues that need to be considered by system designers.

Nygren<sup>226</sup> and Berg<sup>229</sup> have demonstrated that reading medical records is a highly complex task and many features of the layout can aid or hinder the reader. The ability to restructure such elements as the summary chart depending on the requirements of the user will aid searching and decision making. Another study showed that the scale on a partogram can alter the likelihood of intervention because of the clinician's perception of the different rate of labour<sup>231</sup>.

**Balance of free text and structured data**

The difficulty of the balance between free text - to aid comprehensive description of the patient, and structured vocabulary to aid automatic processing (e.g. decision support) is still debated. Discrete data elements from a defined vocabulary rather than free text entries are valuable when processes require automation

*...for a CPR to have multiple benefits, the data in the record needs to be structured and coded - at least to some degree. This is difficult to do with textual data.... (Jan. H Brummel<sup>232</sup>)*

Clinical terminologies and vocabularies are evolving rapidly from simple lists of codes and texts to neural networks of concepts and thesauri. Major developments are the merging of SNOMED-RT and the NHS Clinical Terms (Read codes version 3.1) to form SNOMED-CT, and the complex structures enabling natural language processing in GALEN and the UMLS<sup>233,21</sup>.

Decision support is best accepted by health care professionals when integrated with prescribing and other order entry systems. However, although there are a huge array of guidelines and care pathways that have been published, few have been implemented in computer systems. There is a technical difficulty with authoring guidelines (or clinical guidance) in a form that can be processed by computers and is transferable between systems. Tools are required for this purpose and are now being developed in research environments. There are a number of approaches: defining a language which expresses rules (e.g. the Arden syntax or GLIF); producing tables of guidance and rules for how they are implemented (Prodigy Release One); and producing a software component with a defined interface (e.g. Prodigy Release Two).

Protocols and guidelines are beneficial but issues arise when they are applied when the EHR is incomplete. Miller and others have considered appropriate approaches to this problem with immunisation of children<sup>234</sup>.

The benefits of digital information are considerable - enabling transfer, copying and access at a distance. Encoding information such as sounds and images requires a very large amount of digital data compared to text. The increasing digital storage requirements for encoded images and other complex data (see Table 8 below) stretch the capability of modern hardware with a typical USA medical centre generating 3.5 terabytes (Million MB) of data a year.

**TABLE 8.** Size of multimedia components. From Lowe<sup>235</sup>

EHR component	Size
One page of single spaced text	4 KB
640 x 480 pixel 24 bit colour image (e.g. a high resolution microscopic image)	1 MB
Digital AP chest X-ray (2048 x 2048 pixel)	8 MB
'Typical' head MRI	20 MB
'Typical' chest CT Scan	50 MB

#### • Implications for a national approach in Australia

- ◆ The technical difficulties facing EHR development are considerable and much work is progressing on many fronts. These difficulties will not be resolved in the short term and others are likely to arise. A national approach must determine which are the highest priority and may be overcome or substantially contributed to with a national effort - specifically:
  - issues with web based federated systems that straddle multiple sites;
  - specialised query languages and databases for health records;
  - experiments with EHR transfer using GEHR and PRA and subsequent integrity analysis;
  - trials of data entry solutions in clinical settings;
- ◆ Cooperation with international efforts to achieve natural language processing in health care needs to be fostered.

## 5.5 FINANCIAL DIFFICULTIES

Australia has a complex funding model and multiple agencies determining policy. Federal funding only accounts for 45% of the total health spending in Australia. Any approach undertaken will need to be acceptable to the private sector as well as the States and Territories if it is to be embraced. Costs will almost certainly outweigh the benefit in first year<sup>211</sup>, and may be more than can be afforded<sup>107</sup>.

True costs of a medium sized hospital CPR system was estimated in 1991 at between US\$2 million and US\$6 million in the Institute of Medicine report. Others estimate it to



be as high as US\$40 million depending on the size, systems already in place and other considerations<sup>236</sup>. No one has made a similar estimate since. Efforts to find large scale solutions in Australia described in Section 6.4.3 on page 92 have been expensive - in the range of AUS\$20-60 million. Accurate costings remain problematic<sup>128</sup> not just in health care<sup>19</sup> but in many industries. Service industries stand to gain the most in productivity from the use of IT but implementations in these industries are sometimes the least cost-effective. Implementation is often ceased for financial reasons, for instance data entry costs reaching 17% of billing<sup>117</sup>.

Further, financial gain alone may become the focus of EHR implementations<sup>135</sup>, but as two comparative studies in Australia have concluded, cost of systems has been a high priority barrier to the uptake of computerisation by health professionals in primary care<sup>213,214</sup>. This appears to have been overcome by the recent introduction of incentives through the GPCG (see Section 7.1.1 on page 97).

Financial difficulties may be associated with lack of involvement of clinicians at the time of implementation. An example is the University of Virginia Medical Center system which was strongly opposed by physicians because it lacked sponsorship by clinicians, altered traditional working arrangements, changed professional relationships and constrained the medical education program. The system was eventually installed 3 years behind schedule at a cost which was three times that estimated<sup>105</sup>. Following such experiences, health professionals resent the opportunity cost of EHR systems with some justification.

There is obviously a need to limit the cost of EHR development. Countries like South Africa have a total health care budget that is roughly equal to the funding for Harvard Medical School and Massachusetts General Hospital<sup>14</sup>. Open source system development such as the LittleFish project is probably the only option for such situations.

**• Implications for a national approach in Australia**

- 
- ◆ Any national approach will need to take into account the structure of the Australian health system and its funding.
  - ◆ Open Source developments - a cooperative software development model - warrant investigation as part of a national approach.
-

## Part 6 National approaches



This part of the report outlines several examples of national or regional approaches to the implementation of electronic health records in both primary and secondary care. First, detailed case studies of national approaches to the development and implementation of electronic health records in the United Kingdom, New Zealand and Canada are provided because their health and economic systems are very similar to our own. As *Health Online* acknowledges<sup>2:p11</sup>, these countries have recognised the need for a national and strategic approach to utilising the benefits of information technology in health care “*in order to secure promised advantages for the nation as a whole*”. It is hoped that taking a national approach “*will minimise the risks that might otherwise occur through ad hoc (and therefore likely incompatible) activities*”. These three examples are followed by a summary of the development and implementation of EHRs in Europe and the USA. Lastly a brief overview of state and territory initiatives is provided.

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### 6.1 UNITED KINGDOM

#### 6.1.1 SUMMARY OF UK PLAN

The UK approach towards electronic health records is reflected in *Information for Health*, the information management and technology strategy for the National Health Service, published in 1999<sup>237</sup>. This charts a five-year evolution for hospital and primary care information systems, together with a number of other complementary health informatics projects. It now provides the blueprint for all new funded measures within the NHS Information Authority and the Policy Unit<sup>238</sup>. The key measures within *Information for Health* relating to electronic health care record information are:

- a six-level progression towards electronic patient records within hospitals;
- an electronic health record anchored in general practice;
- extensions to the NHS strategic messaging service;
- the use of NHSnet<sup>240</sup> for many clinical and management communications between purchasers and providers;
- the launch of a national electronic library for health;
- the application of telemedicine services; and
- programmes for informatics education for health care professionals.

The NHS has had a patient identification number for many years. It is issued at birth as part of the registration process. A comprehensive system for using temporary numbers in acute health care has been developed which are resolved at a later time following electronic communication with the national centre which maintains the numbering system. A new format of number has been developed to support electronic communications, removing coded information from the number which could be deciphered with minimal effort.

The UK NHS has chosen to draw a distinction between:

1. comprehensive electronic patient records that might be implemented within a single hospital trust (known as the EPR); and
2. longitudinal records that would be based on a GP electronic health record with summary information from a number of hospitals and some community services (known as the EHR).

This distinction does not appear to be drawn from any recognised nomenclature, but has now become an accepted understanding inside the UK NHS.

Hospital Trusts are expected to progress towards full EPRs through a series of stages (Levels) as shown in Table 1 below.

**TABLE 9.** Six levels of progression towards EPRs in the NHS Plan

<b>EPR Levels</b>	<b>Description</b>
1	Patient administration and independent departmental systems
2	Level 1 plus integration via master patient index
3	Level 2 plus electronic clinical orders, results reporting, prescribing, multi-professional Integrated Care Pathways
4	Level 3 plus access to knowledgebases, embedded guidelines, electronic alerts, rules, expert system support
5	Level 4 plus specific clinical modules, document imaging
6	Level 5 plus telemedicine, other multi-media applications (e.g. PACS)

The NHS vision of the EHR is of a longitudinal patient record, anchored in general practice and possibly delivered through extensions to present GP systems. There needs to be 24 hour clinician access to the EHR within the NHS. It must incorporate health and social care interfaces, supporting seamless care between GPs, hospitals, and the community. The implementation of EHR systems must conform to NHS technology standards, security & confidentiality policies. It must utilise the existing and planned NHS technical infrastructure: NHS wide network, the strategic messaging service (based on [EDIFACT](#)), NHS clinical terms (presently the Read codes, in future to be [SNOMED-CT](#)). Pilot EHR implementations will be demonstrated through "Beacon Sites", which are being identified for accelerated implementation to illustrate and disseminate the practical means of realising EHRs.

Specific targets have been set for the attainment of EPRs and EHRs over the next five years. These are summarised in Table 2 below.

**TABLE 10.** Information For Health Targets

Target	Description
<b>Date</b>	<b>March 2000</b>
T1	Ensuring the NHS copes with the Year 2000 problem
T2	Developing initial Local Implementation Strategies (and agreeing them with Regional Offices)
T3	Completion of essential infrastructure
T4	Connecting all computerised GP practices to NHSnet
T5	Offering NHS Direct services to the whole population
T6	Completing the national NHS email project
T7	Establishing local Health Informatics Services
T8	Completion of cancer information strategy
T9	Beacon EHR sites complete plans
T10	35% of all acute hospitals to have implemented a level 3 EPR
T11	Substantial progress in implementing integrated primary care and community EPRs in 25% of Health Authorities
T12	Using NHSnet for appointment booking, referrals discharge information, radiology and laboratory requests and results in all parts of the country
T13	Community prescribing with electronic links to GPs and the Prescription Pricing Authority
T14	Telemedicine and telecare options considered routinely in all Health Improvement Programmes
T15	A National Electronic Library for Health accessible through local intranets in all NHS organisations
T16	Information strategies as appropriate to underpin completed National Service Frameworks
T17	Demonstrator EHR sites have an initial first generation EHR in operation
<b>Date</b>	<b>March 2005</b>
T18	Full implementation at primary care level of first generation person-based Electronic Health Records
T19	All acute hospitals with level 3 EPRs
T20	The electronic transfer of patient records between GPs
T21	24 hour emergency care access to relevant information from patient records

## 6.1.2 PROGRESS TO DATE

### ***Information for Health: Implementation Strategies***

Individual Health Authorities have been invited to submit proposals for their Local Implementation Strategy (LIS) for *Information for Health*. These proposals may include bids for EHR Beacon Status, and were submitted by April 2000 with the final NHS selection expected by early summer 2000.

The core themes within each LIS include plans for developing:

- secondary & tertiary care services (towards EPR level 3 or higher);
- integrated primary & community care<sup>239</sup> (which includes developing general practice & community systems, integrated clinical systems for primary health care teams and the integration of NHS Direct & Walk-In Centres;
- integrated health & social care, including mental health services;
- initiatives to improve the quality of care such as the new National Service Frameworks for specific clinical services such as cancer and cardiac care, general clinical data quality issues and prescribing;
- information for clinicians, patients and the public;
- education, training and development; and
- security & confidentiality.

The present reality of legacy technology infrastructures, variable clinical systems functionality and patchy daily use, the duality of electronic and paper-based systems and the enormous training needs for embracing EHR systems means that the journey to a complete and multi-enterprise EHR will take some time. In the interim, the existing systems will remain in use and an early requirement will be to seek ways in which, through training and local professional agreements, the existing clinical systems can be used to best advantage. The goal will be to ensure that the most accurate, complete and consistent health care information is progressively accumulated within each legacy system, for integration as and when these systems are federated or decommissioned. Examples of such policies include the use of agreed clinical terms, data-sets and templates; the progressive reconciliation of patient identifiers and demographic information, fostering collaborations on common care pathways.

### ***EHR Building Blocks: UK NHS Experience***

Considerable work already exists to define the requirements of and possible technical approaches for implementing high quality EHRs. In the UK the former NHS Information Management Group instigated a wide range of projects over many years in building towards an electronic communications infrastructure for the NHS. Amongst the most notable has been the development of a set of standard messages to enable the transfer of managerial and clinical information between purchasers and providers<sup>241</sup> over the new NHS network. The expansion of the initial set of Read codes, through the Clinical Terms Project, aims to provide a "language for health care" for new generations of clinical systems<sup>242</sup>. The Electronic Patient Record Project has highlighted many of the difficulties which must be overcome if the hospital medical record is to be fully computerised<sup>243</sup>. The new NHS Information Strategy defines a formal and funded commitment to the integration of patient records within hospitals (Electronic Patient Records) and across the wider NHS (Electronic Health Records).

Since the late 1980's several EU Member States have adopted specific programmes to promote computerisation, through a combination of systems development programmes and financial incentives schemes, but these have been slow to stimulate the clinical

computing market place. General Practice has been the most progressive health care sector at embracing computer use within direct patient care, particularly in the UK and in the Netherlands where most GPs now capture some elements of the patient encounter on an electronic health care record system<sup>244,245,246</sup>.

UK general practice systems have, over the past ten years, been conformance-tested against progressively more detailed and rigorous functionality and safety criteria. These standards, known as Requirements For Accreditation (RFA) now require the incorporation of PRODIGY<sup>247</sup> (national prescribing guidelines for a wide range of common primary care conditions) and MIQUEST<sup>248</sup> (a remote access audit and population morbidity data extraction and analysis tool, based on Read Codes).

The UK has sought to encourage the migration of clinical systems towards compliance with the new CEN/TC 251 EHCR Communication pre-standard, prENV 13606<sup>249</sup>.

***EHCR Building  
Blocks: The  
Adoption of  
Standards***

Many national, European and international standards have emerged from the R&D results described above. Such standards can potentially facilitate the interoperability between different vendor products. These can enable enterprises to adopt a multi-vendor best of breed solution to local information system requirements whilst remaining consistent with the broader vision of communicable and lifelong health care records across the whole UK NHS and internationally.

The NHS has itself defined many standards for use within and between health care enterprises and health authorities. These have been outlined earlier; they have influenced strongly the specification of clinical information systems marketed in the UK but have varied in their wider influence within Europe.

The most pertinent recent European pre-standard is CEN/TC 251 prENV 13606<sup>249</sup>. This four part standard for EHCR Communication defines:

1. an EHCR architecture (as an information model);
2. a set of term-lists that can be used to name or categorise EHCR entries;
3. a model for the distribution rules applicable to the access to EHCR entries;
4. a set of structured messages to be used when EHCR entries are communicated between EHCR systems.

Much of the background R&D underpinning this standard originates from the GEHR and Synapses projects.

There are endeavours within several EU member states to implement part or all of prENV 13606. A forum will be required through which experience can be shared and cross-member support given. (The CEN Secretariat, though able to receive direct feedback on the ENV through its national representatives, is not funded to perform such a role.) The EU Fourth Framework project EHCR SupA contributed to the four CEN Project Teams involved in drafting this standard, and has provided some guidance material on its interpretation and possible implementation, but is not funded to continue beyond March 2000. Clearly this standard will contribute to the present debate on the EHR-related standards to emerge from ISO/TC 215.

**6.1.3 PERCEIVED  
BENEFITS AND  
DIFFICULTIES**

The perceived benefits<sup>250</sup> and difficulties<sup>251</sup> of the UK approach to EHRs have been debated; the 'devil' being in the detail. It is a huge undertaking and must be managed accordingly.

**Developing a  
Migration Strategy  
Towards EHRs**

Despite considerable progress made, the development of integrated information systems, which can link together clinical knowledge, interventions and records, securely, rigorously, cost-effectively, and at the coalface of practice remains a huge challenge. Achieving the transition from the systems of today to those required to meet the *Information for Health*<sup>237</sup> and Clinical Governance, visions of tomorrow is an extremely complex set of linked clinical, technical and managerial challenges.

Electronic and paper records are presently held in islands of information in independent information systems, each with its own technical characteristics and view of the health care domain. The available evidence on good clinical practice, existing as publications and guidelines, is often too generalised to be applied to individual patient groups, and is isolated from the relevant known facts about any particular patient's medical and social background ref<sup>253</sup>. This evidence is difficult to retrieve at the time and in the location where needed. Health care enterprises and regions therefore need to federate a very large number of physically and technically diverse feeder systems that may be scattered across hospital departments, specialised units, primary care and other community settings<sup>254</sup>.

Most UK Health Authorities comprise hospital and community trusts with a range of legacy information systems; each is pursuing its own pathway towards an enterprise EPR. Each site has an accumulation of local departmental and specialist systems, chosen for their suitability to the teams' requirements but now increasingly holding information that is valuable to others and striving to integrate information that others hold. The opportunity to carry out a "clean sweep" and mop up all such databases into a next-generation EHR system is infrequent and expensive. Even the latest such systems may fail to meet the future requirements for a comprehensive and collaborative EHR, and it is likely that individual systems, developed by smaller players to suit specialist requirements, will always be sought to supplement a core system.

**The benefits of an  
EHR architecture  
standard**

User requirements and any analysis of record entry contexts would form the basis of an Enterprise Viewpoint (ODP Reference Model). The architectures developed from them, often expressed as object models, comprise the Information Viewpoint. Both of these levels of expression can enable implementation in a diversity of computational and engineering methodologies. By remaining at the information viewpoint level, the work on EHCR architectures has continued its independence of any particular implementation and has enabled the models to be re-expressed as relational schemata, pure object-oriented schemata, within messages and as document schemata (such as XML documents).

EHR architectures are normally represented as formal object models, in which each construct is either a class or an attribute. The major focus of work within Europe has been to define the basic (foundation) classes and attributes which form the core model of a patient's record.

The strength of the approach taken in Europe on the EHR architecture (spanning GEHR, EHCR-SupA, Synapses, SynEx and complementary standards from CEN) has been the development of a rigorous generic representation suitable for all kinds of entries, and the requirement for all labelling information to be an integral part of each construct. Provided that the core architecture is common to both a sending and a receiving information system, any health record extract will contain all of the structure and names required for it to be interpreted faithfully on receipt even if its organisation and clinical content have not been "agreed" in advance.

As most EHR architectures have been expressed as object models, interest has grown in the use of object-oriented programming to implement EHR systems and to communicate EHR extracts. The perceived advantage of treating the EHR as a set of objects is that this view corresponds more closely to the actual way health record information is organised than the relational approach.

In contrast to the approach of the EHR architecture groups, several countries have based the communication of clinical data on pre-defined structured messages. The UK is such an example. Although interest within such projects has often been focused on the technical challenges associated with the message representation protocols (e.g. EDIFACT), the telecommunications infrastructures (e.g. electronic mailboxes, X25 and X400 protocols) and the means by which patients, senders and recipients are identified, the principal clinical challenge is in the definition of the information content of each message type.

The message-based projects in Europe and in the US (where HL7 has been widely implemented) originated in the need to support efficient health care administration and finance. Data sets of this kind tend to be stable and well structured, with little need for variation between patients or enterprises.

This contrasts with the idiosyncratic nature of clinical practice and of most health record entries. The need for each clinical message to contain a predictable content structure has inevitably led to their introduction for clinical administration, laboratory results, screening programmes and for the management of well-defined chronic diseases.

prENV 13606-4 now provides a more sophisticated message definition matching the generic approach of an EHCR architecture. HL7 version 3, which is undergoing a series of revisions in draft, is also now attempting a more generic representation of a health record. Implementation experience of such complex messages is limited, and the case for a regional or national approach to EHCR communication based around a long list of formal messages is now less convincing in contrast to the opportunities of exploiting secure distributed computing environments.

Possibly the richest set of implementation experiences to date of a generic and comprehensive EHR originate from the Synapses project<sup>255</sup>. Whilst some common features exist between these examples and the GEHR approach, Synapses has additionally considered a number of the issues involved in sharing EHR information through distributed systems.

EHRs will in practice need to be implemented within a secure communications infrastructure that allows for the seamless integration of existing (legacy) computer systems whilst these remain in use, for the ongoing inclusion of new-generation systems and for the future adoption of new specialist clinical databases. The likely scenario for the initial delivery of local or regional EHRs will be as a secure web-browsable view of sensitively amalgamated multi-site health care information derived from nominated data sets within selected "donor" feeder systems.

#### • **Implications for a national approach in Australia**

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- ◆ Ellis and Kidd<sup>218</sup> have summarised the lessons to be learned from an Australian perspective. They state that there is:
  - a lack of education, training and support;



- no common data model;
  - no common coding scheme - Read version 2 and version 3;
  - a lack of information exchange;
  - the lack of a reasonable business case to encourage uptake;
  - a lack of validation and verification procedures leading to poor quality data;
  - a lack skilled IT professionals to provide support; and
  - security and confidentiality are not fully addressed (or taught).
- ◆ It must be noted that these problems exist to a far lesser degree in the UK than in Australia. The fact that they have arisen where a great deal has been done at a national level will demonstrate that there is a real need to consider carefully how to proceed in Australia.
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## **6.2 NEW ZEALAND**

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### **6.2.1 SUMMARY OF NATIONAL PLAN**

Since the early 1990s the New Zealand government have been taking a national approach to health information and, since 1995, a coordinated view of the electronic health record<sup>86</sup>. In 1996 the NZ government released a *Health Information Strategy for the Year 2000*<sup>256</sup>. The initial developments involved solving the problem of identifying individuals, providers and consumers, in different settings and ensuring security, confidentiality and privacy of personal health information.

Two national health databases, the National Health Index (NHI) and the Medical Warning System (MWS)<sup>257</sup> are at the centre of the infrastructure that ensures privacy and security as well as access to health care professionals responsible for patient care. The NHI is a register of all users of the health care system in NZ; everybody will be assigned a person identifier (currently between 93% and 95%) and their name, aliases, addresses and dates of birth are maintained. This enables positive unique identification of an individual under strict legislative control of privacy via the 1993 Privacy Act<sup>258</sup>.

The justification for proceeding with the national plan for EHRs<sup>86</sup> can be summarised as:

- Decreased time and therefore cost required for information management of health records;
- Improved availability, transfer, retrieval, and shareability;
- Linkage of health records for a particular patient from different health record sources;
- Decreased cost of health record storage;
- Multiple dynamic views of the EHR obtainable "instantly";
- Powerful abstraction and reporting capability by EHR systems for population health, audit, research and health service planning;
- Improved data quality and standards - via data entry validity checking, and direct data transfer from other sources eliminating transcription errors; and
- Provides underpinning for computer-assisted decision support.

The difficulties raised in the EHR report<sup>86</sup> by the NZHIS were:

- [lack of] confidence in computers amongst their users, and especially in the availability, privacy and security of data stored on computer;
- adoption of a positive attitude towards computers in the work-place;
- require careful strategic management of change, as well as champions for the new technology;
- recognition and acceptance by those entering data that the usefulness of records extends beyond the needs of care of the patient;
- [recognition] that there are many legitimate re-uses of clinical information which are in the best interests of community as well as of various other parts of the organisation (e.g. billing, research, statistics); and
- users [need to] become knowledgeable consumers of this technology (like a motorist) without needing to be experienced in its maintenance (like a mechanic) with adequate skills and proficiency in the use of the computer application.

This report<sup>86</sup> concludes:

*It could be argued that there is a strong business case for the development and implementation of computer-based medical records. All the necessary technology for implementation of full electronic medical records exists. Where electronic records are kept as an integral part of the care planning and delivery process, their data quality is normally high, and almost all the administrative requirements for data can be provided as a by-product of these records.*

## **6.2.2 PROGRESS TO DATE**

### ***Primary care***

New Zealand GPs have had a significantly higher level of computerised information management experience over the past decade than their Australian counterparts. It is estimated that 95% of NZ GP practices use practice management software<sup>259</sup> and over 50% use computerised patient management systems (prescribing, clinical notes, decision support etc.)<sup>260</sup>. Some Independent Practitioner Associations (IPAs) such as East Health and Rotorua claim about 85% of their GPs use clinical patient management software. Furthermore, all of these have some form of EHR<sup>260</sup>. It should be noted that all of the main GP software vendors in New Zealand have included clinical notes and patient-centred EHR functionality for many years and in some cases more than a decade. Accordingly, most GPs with clinical systems use an EHR for at least a part of their clinical data recording<sup>261</sup>. This contrasts with the Australian situation where the emphasis to date has been on electronic prescribing with only a very low level of EHR use (about 5%) by Australian GPs.

New Zealand GPs also appear to have a much higher usage of the internet than Australian GPs. A recent survey showed that 72% of NZ GPs had used the internet and 81% of these use it for work-related tasks such as knowledge update, patient information, and communication with colleagues<sup>262</sup>. However, only 30% said they use the internet at least weekly to update knowledge and only 7% said the internet had improved their relationship with patients.

<b>Secondary care</b>	<p>The use of computers in New Zealand hospitals over the past decade has, as in Australia, concentrated mainly on administrative and financial applications. Clinical computing has mainly been limited to departmental systems such as pathology, radiology, and pharmacy. However, a number of New Zealand hospitals (e.g. Auckland, Wellington, Waikato) are now actively planning or implementing integrated information systems and there has been significant recent development towards IT support for integrated patient care (mostly disease management led)<sup>260,263</sup>.</p>
<b>EHR standards development</b>	<p>New Zealand is one of the few countries in the world which has made any attempt to develop a national EHR standard. A draft version of an "Electronic Medical Record" standard was published in 1998<sup>263</sup>. The draft NZ standard has adopted an object-oriented architectural approach. Its basic structure has much in common with GEHR but has extended somewhat into areas of medical process such as episodes of care (GEHR is also now being extended to cover process issues).</p> <p>There has, however, been no further development of the draft EHR standard published since 1998. This is mainly because work by the committee since that time has shifted to active participation in ISO/TC 215 projects on the EHR to promote the adoption of EHR standards internationally<sup>264</sup>.</p>
<b>Progress on EHR building blocks</b>	<p>New Zealand is well advanced on developing the EHR building blocks. A number of these are considered below.</p>
• <i>National Health Index (NHI)</i>	<p>The NHI<sup>257</sup> was first introduced in 1977 to assist public hospitals in managing patient files and uniquely identifying patients. The NHI consists of a seven character unique identifier and a number of demographic data elements including name, address(s), date-of-birth, sex, ethnicity, and aliases.</p> <p>The NHI is now used in both secondary and primary care and the NHI is used to access an increasing number of applications. GPs currently have at least 80% and up to 99% of their patient registers indexed<sup>264</sup>. All users of the NHI are bound by the NZ Privacy Act (1993) and the NZ Health Privacy Code<sup>265</sup>. There is also a specific access agreement between the NZHIS and individual users.</p>
• <i>The Medical Warning System (MWS)</i>	<p>The MWS<sup>257</sup> is a national database which serves the function of notifying health care providers of any information or known risk factors that might be important in making decisions about patient care. The MWS uses the NHI number for access and access rights are subject to similar conditions as for the NHI. The MWS has five distinct components which are:</p> <ul style="list-style-type: none"> <li>• Medical Warnings (e.g. allergies, drug sensitivities);</li> <li>• Medical alerts (e.g. diabetic; renal failure requiring dialysis);</li> <li>• health care Event Summaries (e.g. hospital admission date and principal diagnosis);</li> <li>• Contact details (e.g. next-of-kin); and</li> <li>• Donor information (e.g. kidney and heart donor).</li> </ul> <p>Whilst the MWS is potentially a very important national database, it has so far been poorly used by hospitals and essentially not at all in the community<sup>264</sup>.</p>
• <i>Clinical coding</i>	<p>ICD9-CM-A has been used by all New Zealand hospitals and this is now being replaced by the Australian version, ICD-10-AM. The national coding system for pri-</p>

mary care is Read Version 2 which was introduced prior to 1994. Version 3 is available but not yet implemented by any software system.

The usage of Read codes by NZ GPs is thought to be still fairly low although in some IPAs where it is actively encouraged, the usage rates are much higher<sup>264</sup>. Some IPAs have simplified the Read codes for their own use<sup>259</sup>.

A drug chapter for Read in NZ has been developed and was released in The Pharmaceutical Index of New Zealand in January 1999. LOINC codes for pathology and radiology are under review and have so far been implemented by one pathology software vendor (Delphic). LOINC codes are now being used within and between some hospitals and roll-out to GPs is expected in the near future<sup>264</sup>.

• *National Health Data Dictionary*

The New Zealand Health Data Dictionary<sup>266</sup> contains, like Australia's equivalent, only high level demographic and health items which reflects its original purpose as a tool for health service administrators, planners, and policy makers. However, also like Australia, the NZHIS intends to expand the Data Dictionary to include more granular clinical terms and concepts which will greatly increase its utility for health informaticians, clinicians, and software developers.

• *Clinical messaging and other e-health initiatives*

HL7 is the official New Zealand standard for all clinical messaging. It is currently being used for:

- pathology orders and results;
- radiology and results;
- referrals, status, and discharge;
- NHI and MWS transactions; and
- claims and payments.

Electronic clinical messaging for pathology and radiology results in primary care is much more common in New Zealand than Australia with an average of around 65% participation nationally and over 70% in some areas such as South Auckland. This will increase rapidly in the near future because the Government has introduced a requirement that all GP billing claims must be made electronically by July 1, 2000<sup>259</sup>.

NZHIS established a national health Intranet in 1999. It is still in an early stage but will be used for information, messaging, and e-commerce across all sectors of health. The Intranet is expected to eventually replace the current privately run X.25 network which is used extensively for clinical messaging to GPs<sup>252</sup>.

The Intranet architecture has 3 levels of security. Level one uses IP (internet Protocol) on a NZHIS managed Virtual Private Network (VPN). Level 2 creates security with X509 version 3 digital certificates with Public Key Infrastructure. Level 3 uses 128 bit encryption<sup>264</sup>.

### 6.2.3 PERCEIVED BENEFITS AND DIFFICULTIES

Apart from the government reports cited above there is some literature concerning implementation of this national approach. Much of the work has been done on a much smaller scale than in Australia - compare Tilyard's description of the creation of a national general practice minimum data set in NZ<sup>267</sup> with the current work in Australia.

New Zealand have been world leaders in privacy of personal health information, enacting the Privacy Act in July 1993 and the "Health Information Privacy Code" in 1994. The latter<sup>258</sup> formulates rules applicable to:

- collecting personal health information;
- storage and security;
- access and correction;
- use and disclosure;
- updating and disposal; and
- person identifiers.

The responsibility for privacy is unambiguous and rests with named individuals as in the European directive<sup>156</sup>. There is no doubt that this approach has allowed some of the innovations described above to proceed.

The implementation paper from NZHIS<sup>268</sup> raised the issue of change management.

*Change creates uncertainty; where there is uncertainty there is fear and rumour. The management of this requires investment of time and effort, and the use of appropriate ways to involve those who will be affected by it. Staff must be motivated by management to view the change as positive and beneficial and to become committed to it. They must embrace the goals of the change and be prepared to work towards their achievement. In addition, there will need to be serious investment in appropriate education and staff development activities.*

**Government  
interest and  
promotion**

The decision by the New Zealand Government in the early nineties to invest in and promote key items of health information management infrastructure has positioned them as a world leader in the field, particularly in the primary care sector. This infrastructure includes the National Health Index, the Medical Warning System, a national clinical coding system for primary care (Read) as well as for hospitals (ICD), the early adoption of HL7 as the standard for health messaging, and more recently a national health intranet and the attendant security apparatus in the form Public Key Infrastructure (still in early development). National privacy legislation and a national Health Information Privacy Code have also been in place for over six years.

These initiatives have provided the essential building blocks for a national electronic health record implementation. Significant and pioneering work has already been done on a national EHR standard. This, together with the experience gained in the important items of infrastructure listed above, has enabled this small country to now play a major informed role in the development of international standards for the EHR and other areas of health informatics. The New Zealand health software industry has also benefited greatly from this experience with a disproportionate number (compared to Australia) being successful in the international market. These include Cardinal Healthcare, Orion Systems, Delphic, Houston, and Terra Nova. The New Zealand health industry, including ultimately the patients and clinicians, will almost certainly also benefit from this international experience and success.

New Zealand is clearly well ahead of Australia in its implementation and use of EHRs in primary care. Despite this, the lack of an EHR standard to date has led to the same problems found in other countries, with little or no interoperability between different

clinical systems except through simple messaging. New Zealand has benefited from a single vendor implementation of HL7 messages.

The status of the EHR and other aspects of clinical computing in New Zealand hospitals is much the same as in Australia (and most of the rest of the world). There is generally only a Patient Master Index (containing demographic and minimal clinical information in the form of diagnostic coding) plus various departmental systems such as pathology and radiology with little or no inter-operability. There is no integrated patient-centred electronic health record. However, the NZ National Medical Warning System could be seen as the starting point for a national EHR 'regime' and the other items of information infrastructure discussed above will also help to provide a firm foundation.

The single level of government (and hence of health policy and funding) in New Zealand, together with the active involvement of the NZHIS and Ministry of Health in IM/IT policy and implementation over a long period of time, have no doubt contributed significantly to the relative sophistication of health care computing, particularly in primary care. The small population and land mass have probably also played a positive role.

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**• Implications for a national approach in Australia**

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- ◆ The building blocks for a national approach are clear from NZ experience. First, legislation that genuinely addresses consumer concerns regarding privacy in a manner that balances the need for access to safeguard health. Second, regulations which ensure the security mechanisms necessary to achieve this balance.
  - ◆ New Zealand has a single organisation able to make decisions on a national approach to EHR implementation, unlike Australia. Recent initiatives to centralise decision making, such as the formation and funding of NHIMAC, the General Practice Computing Group and the EHR Task Force, are important and likely to encourage progress.
  - ◆ There are more lessons to be learned from the New Zealand experience in the areas of building, implementing, and supporting the infrastructure necessary for an integrated national health information management system. Principal among these are the need for a patient identification number (PIN) and a national coding system for primary care. All of these items are currently being considered in Australia. These processes will benefit from closer dialogue with our New Zealand colleagues so that we can gain from their experience.
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**6.3 CANADA**

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**6.3.1 SUMMARY OF NATIONAL PLAN**

Canada's focus at the national level in establishing EHRs reflects its national-provincial division of responsibility for health care. The Federal government is primarily responsible for ensuring that the provisions in the Canada Health Act are consistently implemented across the country. The Provinces are responsible for managing and operating their respective health care systems. This division of responsibility and its influence on the human, technical and business dimensions of health care is a fundamental factor affecting the planning of any initiative.

Over the last several years, the 'evolutionary' forces of this context have spawned several national initiatives, which have been focused on influencing and facilitating the establishment of EHRs, rather than creating a single prescriptive national plan. There are now a number of organisations, funding programs and initiatives include which are working together to achieve this outcome.

***The Canadian  
Institute for Health  
Information (CIHI)***

The Office of Health and the Information Highway (OHIH) ([www.hc-sc.gc.ca/ohih-bis/menu\\_e.html](http://www.hc-sc.gc.ca/ohih-bis/menu_e.html)), underlines the strong synergy the government sees between technology and health care delivery. The OHIH initiatives include:

- The National Health Surveillance Infostructure (<http://www.hc-sc.gc.ca/hpb/lcdc/webmap/index.html>) - a network of networks with provincial partners and other stakeholders such as medical laboratories and poison control centres. These networks will enable data collection, integration and analysis from diverse sources for risk management - with the aim of saving lives, preventing disease and disability and thus reducing the cost of health services.
- The Canadian Health Network (<http://www.canadian-health-network.ca/customtools/home.html>) - providing well organised, accessible and timely information on health promotion, disease prevention, treatment options and health system performance through multimodal access, including WWW, 1-800 lines, interactive voice response and fax-back. The CHN aims to empower consumers through quality health information and overcome geographic and financial barriers, assisting all Canadians to more actively manage their health.
- The First Nations Health Information System (<http://fnhis-sispn.hc-sc.gc.ca/fnhis/default.htm>) - the system is designed to support case management, health planning and evaluation at the community level in Indigenous communities. The system will aim to ensure universal access to health information management and reduce risk through early detection of disease outbreaks, new diseases and antibiotic resistance. The system will also aim to offer a more comprehensive immunisation schedule management and communicable disease control.
- The Health Infostructure Support Program (HISP) ([http://www.hc-sc.gc.ca/ohih-bis/whatfund/hihsp-intro\\_e.html](http://www.hc-sc.gc.ca/ohih-bis/whatfund/hihsp-intro_e.html)) - established in March 1998 to support efforts to test and assess the use of new information technologies and applications in the health field through pilot projects in areas such as public health, health surveillance, pharmacare, First Nations health, homecare and telehealth. It was open to non-profit, non-government groups and organisations in Canada. Thirty-six pilot projects were, or are currently being conducted by 33 non-profit, non-governmental groups and organisations in the health sector. The federal government will provide \$8.7 million while private sector financial support in excess of \$2.25 million has been committed to the applicants.

Health Canada's Office of Health and the Information Highway (OHIH) has now announced the Canada Health Infostructure Partnerships Program (CHIPP). "CHIPP is a two-year, \$80 million, shared-cost incentive program, aimed at supporting the implementation of innovative applications of information and communications technologies (ICT) to bring better health and health services to Canadians. CHIPP will support projects in two strategic areas of ICT-based innovations in health care delivery, namely telehealth (telemedicine and telehomecare) and electronic health records (EHRs)."

This is the first national initiative that is directly focused on the creation of EHRs. The rationale for the program is as follows:

*EHRs are the essential health information related to individuals and health care providers. They normally include the individuals' health information and unique identifier code; the identifier code for the health facility providing the service, the health care providers' code; and other relevant information.*

*Having individual EPRs is important, but linking and sharing patient records across health care providers, i.e., building an EHR, will create a paradigm shift resulting in a patient-centred integration of health care as well as more streamlined health administration and more informed policy making.*

**The Canadian  
Institute for Health  
Information (CIHI)**

The Canadian Institute for Health Information (CIHI) (<http://www.cihi.ca>) - plays a critical role in the development of Canada's health information system. CIHI is a federally chartered but independent, not-for-profit organization. It brings programs, functions and activities from The Hospital Medical Records Institute (HMRI), The MIS Group, Health Canada (Health Information Division) and Statistics Canada (Health Statistics Division) together under one roof. Its primary functions, which relate to the establishment of national EHRs, include:

- Identifying health information needs and priorities;
- Collecting, processing and maintaining data for a comprehensive and growing number of health databases and registries, covering health human resources, health services and health expenditures;
- Setting national standards for financial, statistical and clinical data as well as standards for health informatics/telematics

Specific initiatives that CIHI has initiated include:

- The Roadmap Initiative (<http://www.cihi.ca/Roadmap/rdindex.htm>) - a national vision and four-year action plan to modernize Canada's health information system. Led by CIHI, it is a collaborative effort with Statistics Canada, Health Canada and many other groups at the national, regional and local levels.
- The National Data Model and Dictionary Project ([http://www.cihi.ca/Roadmap/Health\\_Data/start.htm](http://www.cihi.ca/Roadmap/Health_Data/start.htm)) - the Conceptual Health Data Model (CHDM) is a reference tool for organizing high-level health information and data. The CHDM provides a framework within which to view and define health information. The goal of this project is to further enhance the CHDM developed by the Partnership for Health Information Standards. Specific objectives include:
  - Mapping the Conceptual Health Data Model to an existing logical data model used by a significant number of stakeholders in Canada;
  - Creating and publishing a standard data dictionary for CIHI entities and data elements; and
  - Developing communication and education material to facilitate the use and acceptance of the CHDM.

**Federally Funded  
Provincial  
Initiatives**

Transfer payments and funding initiatives from the Federal Government have directly and indirectly spawned several projects, which have added to the national experience in establishing EHRs. The most notable project at the Primary Care level is Ontario's Primary Care Reform initiative ([http://www.gov.on.ca/MOH/english/pub/pub\\_links/pub\\_pricare.html](http://www.gov.on.ca/MOH/english/pub/pub_links/pub_pricare.html)).



The \$18 million initiative consists of a number of pilot projects, which are being jointly coordinated by the Ministry of Health and Long-Term Care and the Ontario Medical Association. As of July 1999, 40 doctors had already formed Networks. Another 80 family doctors are expected to establish other Networks in the coming months. Nearly 300,000 Ontarians will be invited by their doctors to enrol with them, as part of a pilot project.

Primary Care Networks (PCNs), which consist of groups of family physicians, will be required as part of the project to select and implement primary care EPRs. The goal is to use information technology to enable transformation of the primary care component of the healthcare system.

### 6.3.2 PROGRESS TO DATE

Information Highway and Canadian Health Info-Structure were announced in 1996 and 1997 - to investigate the use of information technology to assist the health sector to move rapidly towards an evidence-based health system. The barriers to such a system were seen as:

- lack of information on which to base decisions;
- lack of access to information when required;
- lack of agreement on which information is reliable;
- lack of longitudinal data; and
- difficulties in selection of information on which to base decisions.

The Health Info-Structure sought to develop accessible, reliable and consistent information to improve decision-making at all levels. This info-structure was envisaged as a 'virtual information centre' that "is created and used by communities and individuals across Canada. It will be open and accessible, yet assure sufficient confidentiality and privacy to assist decision making by health professionals and patients: support research and training; facilitate management of the health system; and respond to the health information needs of the public."

<b>1994</b>	The Canadian Institute of Health Information was established. CIHI recently received a substantial injection of funds from the Federal Government to pursue its mandate, which in turn will help contribute to the establishment of national EHRs.
<b>1997</b>	Health Canada established an Advisory Council on Health Infostructure to develop a strategy for implementing a nation-wide health information infrastructure - hence 'infostructure' for short.
<b>1998</b>	A major conference was convened by the Council on Health Infostructure and a number of background papers produced by the Information Highway Advisory Council, the Canadian Network for Research, Industry and Education, the National Forum on Health, Industry Canada and Justice Canada. These covered protection of health information and privacy, overall strategy and future vision, related technology initiatives including telehealth, implication for legacy systems, community and consumer views, as well as access and equity. Attendees were also invited to consider a number of Australian initiatives.
<b>1999</b>	The Advisory Councils final report - Canada Health Infoway: Paths to better health - was published in February 1999 <sup>175</sup> . It synthesises the outcomes of the conference, background papers and other materials.

As discussed earlier Health Canada also established the Health Infostructure Support Program (HISP). This program had a very broad mandate and supported many projects. Only a small number of the projects contribute in some way to the establishment of national EHRs.

HISP's successor is the CHIPP program. The program has two focus areas, electronic health records and telehealth. The level of funding and more directed approach promise to create significant progress in the creation of National EHRs.

A number of years ago Canada and the European Community signed an agreement to share knowledge and innovation in healthcare "telematics." Although there have been some joint projects the agreement has not been leveraged to take advantage of its full potential. Recently there have been renewed discussions to determine what kind initiatives could raise the level of co-operation and collaboration.

In the area of Primary Care EHRs, physician groups in the Ontario PCR initiative have completed the evaluation and selection process for their software and hardware. Some sites have actually completed installation of both hardware and software. It is not clear when they will be able to connect to each other and other components of the healthcare ecosystem.

### 6.3.3 PERCEIVED BENEFITS AND DIFFICULTIES

Although Canada has not had a specifically focused national plan for establishing EHRs, the various projects and initiatives undertaken to date have essentially laid the groundwork for a national approach. The work done so far can be characterized as a national independent learning exercise. One could easily criticize it by saying that is has been too painful and inefficient. Nonetheless, it also has been an essential step in creating a critical mass of awareness, understanding and commitment to establishing EHRs. Some of the lessons learned so far are:

***Large amounts of money do not ensure success***

Generous funding has more often been a curse than a blessing while moving up the learning curve. There have been several multi-million dollar initiatives across the country that have yet to demonstrate the ability to assemble and share comprehensive health records. It seems that "big bang" approaches have tended to bog down in the inertia created by the big politics, risk aversion and traditional command and control models, which they attract.

***We need a paradigm shift to succeed***

There is consensus amongst all the stakeholders that the time has come for fundamental innovation. One of the key insights of a joint working group formed by the Information Technology Association of Canada (ITAC) - Ontario Health Committee and the Ontario Health Providers Alliance (OHPA) is that, to quote Albert Einstein:

*The significant problems we face cannot be solved at the same level of thinking we were at when we created them.*

In other words the tools and processes we used to create the current impediments to establishing EHRs will not likely provide the solutions we need. This is fuelling a growing desire and sense of urgency to innovate and collaborate at a local, national and global level to achieve what is essentially a globally shared vision.

A promising development is the growing interest in the application of the Open Source paradigm to the development of healthcare software and in particular to EHRs and the development of community based health information networks. An early adopter is the McMaster Primary Care Network (PCN), which has been established by the Department of Family Medicine, McMaster University in Hamilton Ontario, to participate in

**Healthcare  
behaves like an  
ecosystem**

Ontario's Primary Care Reform initiative. The McMaster PCN is basing its strategy on MUFFIN, a primary care EPR that has been available on an open source basis for nearly ten years. MUFFIN is unique in that it supports teaching, research, evaluation and delivery of care. One of the goals of the PCN is to modernize MUFFIN, create a self-sustaining, open source based strategy for its continued improvement and evolution, and to develop a truly systemic EHR solution for primary care.

One reason traditional business processes and IT solutions have not produced successful EHRs is because healthcare is a "Complex Adaptive System"<sup>207</sup>. It is also highly collaborative in non-competitive healthcare systems such as in Canada. The genealogy of development processes, software components and licensing models for current EHR solutions is essentially the same as that of competitive industries such as finance and manufacturing. It is becoming apparent that the resulting competitive barriers which are embedded in the "genetic code" of existing EHR software components are in fact a barrier to innovation and progress in collaborative healthcare ecosystems. Concrete evidence of this is the huge investment being made by hospitals and regional health networks to integrate their legacy and "best of breed" systems.

In summary, the recently announced CHIPP program has the benefit of building on the experience gained in the various primary care, hospital, regional and provincial initiatives that have been implemented independently across the Canada. CHIPP has the potential of funnelling this experience into a manageable number of integrated national projects. A critical success factor for the CHIPP program is how well it can leverage the knowledge and experience gained in EHRs initiatives across Canada and in other countries with similar health systems.

Key documents, which provide some perspective on Canada's approach and experience in establishing EHRs can be found in the Appendix to this report - Section 9.3 on page 126.

**• Implications for a national approach in Australia**

- ◆ A federal agency that has a mandate to develop the infrastructure and building blocks of the EHR would appear to be a useful strategy to speeding a coherent national response.
- ◆ Business models that operate in EHR development that differ greatly from those operating in the health care system may need greater regulation to meet the requirements of consumers and health professionals.

## 6.4 FURTHER EXAMPLES

### 6.4.1 EUROPEAN APPROACHES

Europe has been a major centre of research and development of EHRs and surrounding technologies. Use of computers in primary care is much higher in Europe than any other part of the world including Canada and the USA<sup>1</sup>, with it being particularly advanced in the Netherlands and Germany. Hospital information systems in Europe rarely contain patient record data other than pathology reports, medication or diagnostic terms<sup>120</sup>. Many are 'home grown' - commercial systems usually being sourced from the USA.

A number of publications describe the European efforts to introduce a framework to support EHR development<sup>120,14,258</sup>. The European Commission's (EC) directive<sup>156</sup> to require consistent legislation in all countries is aimed at providing a safe environment for 'data subjects' while encouraging transfer of information between countries.

The drivers for uptake of computerisation of health care have been varied but usually associated with government requirements or incentives. Germany, for instance, has implemented a health card - key information on a smart card. France requires physicians to submit their bills electronically. The Advanced Informatics in Medicine (AIM) program, funded by the EC, is the largest research and development effort in health informatics in the world. The program has been operational since 1989 and currently sponsors more than 100 major research projects; many are related to supporting EHR development.

One project in the AIM Fourth Framework is the PROREC project (PROmotion strategy for European electronic healthcare RECORDs) promoting and coordinating European wide convergence towards comprehensive, communicable and secure EHRs. This project has issued the Lisbon Declaration<sup>271</sup>.

It is recommended that the Member States through the Commission promote a framework for action within Europe to further develop common aspects of the Electronic Healthcare Records based on the following.

- The EHR is the nucleus of the relationship between the patient, the healthcare delivery system and its professionals. As such the EHR should be the core of the new generation of health information systems.
- The main objective of the use of any EHR must be to improve quality in care by having the record and its associated information always available for the healthcare professionals when needed at the point of care.
- The use of EHRs should lead to direct benefits for the professionals by making their work more efficient. This will arise from supporting the diagnostic process, enhancing EHR accuracy and completeness, improving medical knowledge and disease management, and allowing better preventive care and patient handling.
- Within healthcare systems, either at European, national, regional or local level, the use of appropriate EHRs will also contribute to adequate planning and resource management, facilitation of continuity of care, registration of healthcare interventions, improvement of epidemiological and morbidity information, and hence, a more cost-effective care process.
- The European citizen shall by means of any EHR have (1) a guaranteed right of access to the healthcare to which he is entitled, (2) right of access to his individual data and related services, (3) the effective protection of his right of free circulation with respect to the confidentiality of his individual data.
- Further actions and developments of EHRs should be based upon standards and consensus that ensure interoperability, and allow EHRs coming from different origins to be reliable, communicable, recognisable and comparable.
- The European health telematics industry is to tackle the need for the development of new products in a huge and growing market, offering enabling technology to fulfil user requirements. Multimedia, 3D images, interchange formats, message contents, linguistic barriers and suitable user interfaces are among the challenges to be overcome in a framework of confidentiality and security for patient data.

- The effective cooperation between all interested parties including users, consumers, health professionals, authorities, industry, standardisation bodies and others at a European level and through a process of managed convergence towards European EHRs, would benefit from the establishment of an appropriate structure based on existing organisations that could promote that mission.
- In order to achieve these goals and to encompass the future, Member States individually and through the Commission should encourage common efforts and policies through adequate resource allocation, focusing on the European EHR, and leading us to patient-centred healthcare systems.

**General Practice,  
Holland**

An example of a national implementation is general practice in the Netherlands (see page 39) where in 1996 26% were reported to have adopted a paperless office<sup>194</sup>. Dutch general practitioners have implemented a data model for use in primary care which uses the ICPC reason for encounter as its primary data element - more recently organised into episodes of care. These episodes are not limited by time or place, but remain active until resolution (or death)<sup>272</sup>.

**CEN**

The Centre for European Normalisation (CEN) is funded to develop standards where they are deemed necessary. CEN has been more interested in EHR architectures than its American counterpart (HL7), stimulated by AIM projects such as the Good European Health Record, NUCLEUS, SYNAPSES, EHRA SupA etc. There are a number of CEN prestandards describing aspects of the EHR which can be found at [www.cen251.org](http://www.cen251.org). There has also been considerable effort to standardise patient recognition across Europe through information held on a smart card<sup>258</sup>.

The key elements of the European data protection principles have been summarised by Rigby<sup>273</sup> and are presented in Table 11 below.

**TABLE 11.** European data protection principles and related national legislation from Rigby<sup>273</sup>

Principle	Legal requirement
Fair obtaining	Personal data shall be obtained and processed lawfully and fairly
Purposeful	Personal data shall be held only for one or more specified and lawful purposes
Limited use and disclosure	Personal data held for any purpose shall not be used or disclosed in any manner incompatible with that purpose
Relevant	Personal data held for any purpose shall be adequate, relevant, and not excessive for that purpose
Accuracy	Personal information shall be accurate and, where necessary, kept up to date
Limited retention	Personal data held for any purpose shall not be kept longer than is necessary for that purpose
Subject access	An individual shall be entitled to access to any personal data and, where appropriate, have such data corrected or erased
Data security	Appropriate security measures shall be taken against unauthorised access to personal data and against accidental loss or destruction

#### 6.4.2 THE UNITED STATES OF AMERICA

Legal issues and privacy has been investigated over a long period<sup>46</sup> in the USA culminating in “For the record” report<sup>75</sup> by a large federal team. This is the premier reference document addressing these issues. Despite this national legislation remains a major barrier to implementation of EHRs in America<sup>21</sup>, demonstrating that the political will needs to be there.

##### *Slow uptake*

Implementation of the EHR has been very slow in some areas, and uptake of these implementations has been limited. A survey in 1998 showed that only 9% of 360 acute care hospitals in the USA had computerised a wide range of functions and that not a single hospital had integrated these into a network. Further, tasks such as order entry are only available in 32% of more than 1000 hospitals surveyed in 1998<sup>214</sup>. In those hospitals having order entry systems more than half report that less than 10% of clinicians use the system and less than 10% of orders are made using computers. Only in 4.9% of hospitals are clinicians required to use the system. For instance, the Joint Commission on Accreditation of Healthcare Organisations lists 344 clinical decision support systems it has approved. In January 1999 one hundred of these systems were commercially available and yet none of them had been tested or implemented by a provider of health care services<sup>105</sup>. In group practices in the community no more than 5% use computerised patient records<sup>105</sup>.

The Computerised Patient Record Institute ([www.cpri.org](http://www.cpri.org)) was established in January 1992 charged by the Institute of Medicine with the following objectives<sup>21</sup>:

- support the effective, efficient use of computerised patient records;
- educate change agents and stakeholders about the value of CPRs in improving patient care;
- foster the EHR as the primary vehicle for collecting data; and
- promote the development and use of standards for EHR security and data content, structures and vocabulary.

##### *Leading standards efforts*

The USA is very active in the international standardisation efforts, largely through what has become an international cooperative non-profit organisation - Health Level Seven or [HL7](#). This agency has now become responsible for development of HL7 messages, an XML document patient record architecture (PRA) and other key areas such as a standard expression of decision support rules called the Arden Syntax. Interoperability of software components on the clinical workstation is approached through Clinical Context Object Working Group ([CCOW](#)) to enable ‘federation’ of existing legacy systems and integration of new systems. Another major effort is being undertaken within the Open Management Group (OMG) called CORBAMed. This effort aims to standardise communications between applications at a software level.

The Health Insurance Portability and Accountability Act of 1996 outlined a process to adopt national health data standards and health information privacy in the USA. This act<sup>274</sup> ensures health plans undertaking electronic transaction reached compliance within 2 years in regard to:

1. Certain uniform transactions and data elements for health claims;
2. Unique identifiers for individuals, employers, health plans and health care providers;
3. Code sets and classification systems for the data elements of transactions identified;
4. Security standards for health information;

5. Standards for procedures for the electronic transmission and authentication of signatures with respect to the transactions identified.

The most advanced EHR systems are implemented in academic centres, university teaching hospitals, the Department of Veteran Affairs and the Department of Defence<sup>21</sup>. In 1997, there were seven systems that met the CPRI threshold criteria (see page 119) for EHR systems operating in the USA. One of these was in Veteran Affairs, 4 in academic centres and 2 commercially operated. The new G-CPR or government computer-based patient record initiative aims to develop a framework which enables the provision and protection of worldwide life-long health records for current and past members of the armed forces (more than 15 million people). The combined contracts are to be worth more than US\$2.5 billion<sup>258</sup>.

Drivers for the EHR in the USA are from payers. The National Committee for Quality Assurance (USA) has developed the Health Plan Employer Data and Information Set as a standard report card to help employers, who are usually the funders of health insurance in the US, evaluate health plans<sup>21</sup>. Funding models for Medicare have also been introduced requiring standardised data collection to justify billing. Due to the market penetration of Health Plans (or health maintenance organisations) and managed care, pressure to develop true EHRs has increased.

*The evolution of the healthcare system in the United States is what currently drives the development of the [EH]R. As enterprise and regional healthcare systems become the predominant structures for the delivery of care, the goals now center on creating a longitudinal, lifetime [EH]R that integrates all of an individual's data from all sources. (Ed Hammond<sup>14:p8</sup>)*

#### **Remaining barriers**

A list of barriers that remain unresolved from the first edition are identified in 1997 revision of "The Computerised Patient Record"<sup>21</sup>:

- Definition of the EHR - an evolving concept that responds to the health care environment and takes advantage of technological advances;
- Meeting user needs - ensuring that health care professions are direct users of the system through utility and good interfaces;
- Standards - to enable communication between software components (rather than monolithic systems) through patient identification numbers (PIN), content, vocabulary and format of data;
- Legal and social issues - confidentiality, privacy and security involving people policies and legislation;
- Costs and benefits - overcome through more powerful processors, a greater demand for CPRs (and less risk to developers) and public support; and
- Leadership - required to overcome these barriers and must come from the top of organisations.

Tang<sup>21</sup> admits that between 1991 and 1997, "technological advances aside, progress towards the CPRs as envisioned in [the 1991] report has been slower than anticipated." He adds that many barriers to the widespread acceptance and implementation of EHR systems require national concerted action and mandates - even federal legislation - to be overcome. He calls for a "major coordinated national effort with federal funding and strong advisory support from the private sector" to accelerate change in the USA.

### • Implications for a national approach in Australia

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- ◆ Consistent privacy legislation has been addressed across nations within the EC but remains more problematic within federations such as the USA and Australia. Australia has the opportunity to ensure that consumers are protected and that EHR implementation can proceed in a safe and coherent manner for all concerned. Politicians need to be educated on the need for this fundamental building block to be in place for EHR development - more investigations, even the most thorough as carried out in the USA, will not be enough.
  - ◆ Advances in the field of health informatics and EHRs are generally slower than anticipated despite rapid advances in technology. Standards in the EHR domain in the USA and Europe are largely theoretical at this point. There appears to be no reason why implementation of EHRs should not be steady and considered with suitable trials of unproven approaches.
  - ◆ In a de-regulated environment without specific funding for EHR developments, leadership has proved to be a key factor in EHR development<sup>3:p143</sup>.
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#### 6.4.3 REGIONAL APPROACHES IN AUSTRALIA

##### *New South Wales*

Two State developments in Australia are beginning to enter the territory of EHR development - in New South Wales and South Australia. Although quite different, they are both seeking to align with national approaches.

New South Wales has a relatively well developed IT health infrastructure by national standards. This is despite spending less than 1% of their health budget on information technology<sup>158:p21</sup>. Access to knowledgebases via the internet such as the Cochrane Databases and online journals has been a great success and well received by all - especially rural practitioners.

In the recent NSW Health Council review of health services<sup>158:p21</sup>, the council concludes that...

*there is substantial evidence internationally that information technology systems (particularly patient information systems) can be powerful tools to support clinicians to provide care and to provide consumers with both access to more information and more control over their own health records.*

There is a clear direction of a state based approach to EHR development. The recommendation calls for the NSW Health Department to:

*...cooperate closely with the Area health Services and the Commonwealth Government to revise its [Information Management Technology and Telecommunications] strategy to set out a State-wide strategy to develop an Electronic health Record for every individual in NSW.*

The approach undertakes a number of actions:

- to describe what the “record will cover”;



- to set out an agreement with the Commonwealth Government about timing, implementation and funding;
- to detail how privacy and security issues will be resolved;
- to determine how clinicians and consumers will be involved;
- to introduce a patient identification number (PIN);
- to link secondary and primary care; and
- to immediately mandate data and security standards, and develop a classification system.

• *Problems with current systems*

The problems with the current systems are listed as:

- there is no single record of health care;
- there are no formal electronic links between primary care centres, between primary and secondary care, and between hospitals;
- there is no single patient identifier;
- consumers have little or no access to their health records; and
- there is no way to determine the cost of care for an individual who utilises different services.

The report recommends utilising a patient held smart card for their records and a staged approach with informed community debate. These efforts should be investigated in a number of demonstration projects.

The report acknowledges that “there is little point in having a unique identifier that is confined to State-administered services”. There is no mention in the strategy of how this number would be propagated to primary care and the administration required for this approach.

The report prioritises certain changes which may be summarised as:

- the ability to transfer clinical information from Emergency Departments to the wider hospital;
- electronic transfer of hospital discharge information to primary care; and
- electronic transfer of clinical information between hospitals.

**South Australia**

South Australia’s Department of Human Services examined several commercial clinical information systems, and since 1997 has run an intensive pilot study of OACIS in conjunction with the renal units of the four major Adelaide public hospitals.

OACIS is a patient-centric information system, that can integrate a wide range of electronic data, including PMI, ATS, clinical notes, appointments, laboratory results (imaging included) and clinical orders. It does not provide integrated decision support tools, except for a drug interaction module associated with pharmacy ordering. There is no current intent to facilitate consumer access to personal data in the near future.

As at early 2000 it is planned to capitalise on the significant investment to date by extending OACIS to cover eight metropolitan hospitals, where it will be used by all clinical services. This is an initial phase only, the strategy being to eventually network this service state-wide, to country hospitals, smaller metropolitan clinical centres, GP and specialist practices and private hospitals. Clinical data modules will be implemented during 2000 and 2001, with clinical ordering front-end functions to be devel-

oped and installed over the following 2 to 3 years (which will require the creation of interfaces to existing patient-service applications). The practicality of loading pre-existing patient electronic data from major institutions is being examined.

The present-value development and roll-out cost is estimated at around \$55 million, over 5 years. A cost-benefit analysis of tangible benefits only implies that financial break-even will be achieved after 7 years; but with recognition that there are additional less-tangible benefits as well.

The decision to adopt OACIS state-wide has been based in part on a set of “strategic principles”:

- the system must be patient-centred with the objective of establishing a full electronic medical record;
- OACIS should be accepted as much more than a simple substitution of electronic information for existing paper-based information;
- the initial roll-out will be to all clinical units of all major metropolitan hospitals to maximise the benefits in the short term. Further, within this phase, (1) clinical data management will be completed before clinical ordering will be attempted, and (2) any specific tailoring for individual specialities will be introduced last;
- the more general roll-out to smaller metropolitan centres, country centres and private providers will be a later phase(s);
- the capacity of existing IT infrastructure must be reviewed critically in the light of predicted changes in data load and traffic; some of the necessary infrastructure has yet to be established; and
- the pilot project highlighted that implementation management will be critical, especially of process-change and ensuring an appropriate level of clinician ownership and involvement.

However, a set of significant issues (some very fundamental) have been identified as yet unresolved and thus requiring policy and/or technical solutions. The major of these are:

- the desirability of adopting existing standards for the structure of the electronic patient record and for data coding dictionaries;
- a suite of ethical and legal confidentiality and security issues; and
- the necessity for, but difficulty of achieving, a reliable and functional unique patient identification number (PIN)<sup>269</sup>.

There is acknowledgement of the value of a national approach to the PIN but circumstances may dictate that a state-specific option be adopted for the first (metropolitan) roll-out.

In essence, these replicate the important issues identified as generic elsewhere in this report, which highlights the very real risk of duplicating resource-expenditure and of creating potentially incompatible solutions when independent regional developments do not benefit from a coordinated national approach. In recognition of this there have been cooperative discussions with Commonwealth and other States’ agencies, in particular with NSW.

- **Implications for a national approach in Australia**

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- ◆ Regional efforts in Australia are already diverging considerably and are aware that adopting a national approach will reduce their risk and development time as long as there is no delay.
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## Part 7 Introducing a National Approach in Australia



*For a national approach to be effective there will need to be a shared vision to enable the development of a national strategic framework. Ensuring compatibility requires the development and implementation of agreed national standards for the capture, classification, storage, communication and security of information.*<sup>280</sup>

The electronic health record is coming. This part of the report considers the driving forces in primary and secondary care, the possible consequences of a hands off approach and the benefits and difficulties of a national approach. The evaluation of EHR systems is also addressed.

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### 7.1 DRIVING FORCES

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When contemplating a national approach to the EHR it is important to consider the ‘drivers’ within the health care system. Hospitals are being built with large and powerful communications infrastructures and without paper record storage areas. The driving forces for this change are many and varied and involve staff within the State health departments, hospital executives, IT professionals in general, primary and secondary health professionals who are leaders within their health care institutions, software providers to the health sector and more recently the Federal Government. Also, a number of companies with venture capital behind them are seeking to acquire or take a stake in software companies, general practices, pathology providers and other health resources. Their motives are not entirely clear, but they may be trying to introduce cartels or “managed care by stealth”<sup>F/Note1</sup>. This “battle for the doctor’s desktop” is taking place largely within the sphere of the EHR - the information technology provides access to the doctors, who are seen as the brokers of this economic sector.

Consumers are also seen by some players as proxy drivers for the move to an EHR. Companies are providing EHRs on the internet for consumers and hoping to ‘conscript’ health professionals to use their record as the default standard through consumer pressure. This will no doubt be touted as a consumer revolution, but will meet very few of the principles outlined in this report and in the *Health Online* policy document.

There is a trend to move from the support of health care management to supporting patient care. Patient information is more likely to be complete and accurate if it is coherent and developed over a period of time by clinicians and consumers in cooperation. Complete and accurate information is essential for aiding clinical decision making - the single greatest promised benefit of the EHR. It is also important for meaningful

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1. Professor Michael Kidd, Background Briefing, ABC Radio  
Tuesday 4/4/2000

assessment of quality of care, patient outcomes, management planning, policy development, research and education<sup>160</sup>.

*Health Online*<sup>2:p11</sup> states:

*The way ahead must acknowledge the importance of national collaboration*

*The benefits of adopting a national approach are considerable. The cost of information technology systems is high and a relatively small country like Australia needs to be able to maximise such investment through ensuring open architectures with high connectivity and integration are the basis for such investment in both the public and private sectors.*

The potential benefits of adopting a national approach may well be considerable, but barriers remain. Further, it is important to consider the role of government in taking this approach. *Health Online* states<sup>2:p11</sup>:

*The Commonwealth's role is to create the enabling environment, whereby the information framework is sufficiently robust and flexible to accommodate the needs for security, protection of data and intellectual property, professional autonomy and organisational dynamics - and to adopt a leadership and co-ordination role where a national approach is necessary.*

It is not easy to get it right<sup>218</sup>!

#### **7.1.1 PRIMARY CARE**

Australian general practice is rapidly embracing electronic prescribing - encouraged by the introduction of financial incentives. The General Practice Computing Group, the peak body endorsed by the AMA, RACGP and the Commonwealth Government, successfully lobbied for and now manages these incentives. The Divisions of General Practice are promoting this effort and are being encouraged to develop support networks and innovative approaches to information technology. Supported by new capital through acquisition or interest from financiers, the software suppliers are adding clinical records to their products, thus creating a rudimentary EHR. A small (but increasing) proportion of primary care practices are taking steps towards a paperless office.

There are two commercial drug databases with interaction warnings in use. The development process of one has been accredited using ISO criteria and is reviewed externally. Two vocabularies are used, one proprietary and the other based on an extension of the International Classification of Primary Care. Results reporting with pathology companies is widely used, facilitated by simple text messages called PIT format - HL7 is used in very few sites. These enabling technologies are allowing the move to an EHR in a proprietary manner which is not in the interests of doctors or patients.

Pharmacies have been computerised for some time and are presently in a more stagnant role with old software that provides limited functionality. Electronic prescribing trials are beginning and plans to electronically share the medication record between providers have been mooted. There is no standard medication identifier.

Community health centres and community health professionals are beholden to state governments to provide IT and are some way behind general practices. A consortium of states behind the CHIME project is aiming to address this and should see added facili-

ties in this sector this year. The CHIME project has developed another vocabulary for its purposes which has uncertain implications regarding data collected in the future.

### **7.1.2 SECONDARY CARE**

To date, EHR developments in Australian hospitals have been driven by the need to support management, audit, financial processes and planning rather than clinical care. Thus, most hospitals have administrative systems with applications that are geared towards information management rather than supporting clinical care<sup>18</sup>. The implementation of EHRs has been minimal.

There are a variety of systems operating in hospitals - even often within one institution. Some hospitals have invested in whole of institution solutions provided by large international vendors usually from the USA. A New Zealand company is also providing solutions. Beacon sites such as the New Children's Hospital at Westmead (Sydney, NSW), has an EHR 'federated system' providing access to clinical history, reporting, radiology (including images) and prescribing at the bedside<sup>275</sup>.

Communication links between hospitals and primary care are extremely limited nationally; both hospital and GP systems have been slow to implement HL7 - largely because of genuine difficulties in using the standard. All hospitals report their separation data in ICD-10-AM but this vocabulary is not sufficient to support full clinical systems.

Specialists are more likely to using clinical software in private clinics than in hospitals and the systems they use are mostly based on general practice systems. Pathology providers have been computerised for many years and have led the way in providing results to clinicians. They continue to use the PIT format to enable this service.

Hospitals are keen to offer more efficient care and reach higher levels of consumer and professional satisfaction, and in a climate with limited funding the EHR is seen as one method of making progress. Also, large institutions benefit from being leaders in the introduction of technology - attracting motivated staff and gaining national profile.

### **7.1.3 THE IMPLICATIONS OF DOING NOTHING**

With so much uncertainty, a "hands off" approach may seem appealing. However, government representatives, health professionals, academics and IT companies around the world are attempting to develop and deliver the EHR of the future. Some are hoping to achieve dominance through acceptance as an open standard, others through achieving a commanding market share. However, those focusing on the implementation of the EHR cannot compromise their businesses by waiting too long for standards which are difficult to implement. Those with a focus on standards are unwilling to provide rapid solutions to complex problems and to compromise on openness and commonality. Therefore, just having a standard, carefully prepared and balloted - well documented and accepted by a national standards body - does not adjudge the adoption of this standard. A national framework can lead to appropriate compromises between these disparate interests and provide planning and infrastructure to ensure reasonable outcomes.

With the avalanche of activity in the health informatics sector, it is certain that a great deal is going to happen even if no national approach is instituted. However, taking this approach bodes for an uncertain future as the motivation for and sustainability of current activities in the private sector are inherently risky. The current climate of venture capital may alter dramatically in a very short period with disastrous results.

Australia is faced with a challenge - what is the best way to enable the rapid development of the EHR and, at the same time, ensure that potential benefits are fully realised and difficulties minimised? All parties will welcome timely and helpful interventions. Achieving sufficient compliance with these initiatives to ensure those undertaking

implementation are rewarded rather than penalised may still require some pressure. The States are already moving, South Australia and New South Wales in particular. The success of these first steps are dependent on realising a national approach to the EHR.

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## **7.2 POTENTIAL BENEFITS OF INTRODUCING A NATIONAL APPROACH**

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A national approach to the EHR in Australia is almost certainly warranted based on experience from other countries and the divergent approaches that have been implemented to this point. However, the future will be determined to a great extent by decisions made in the present. Charting a national approach requires a creative but cohesive vision and courage.

The benefits of introducing a national approach to EHRs in Australia are described below and are presented under the ‘party’ deriving most benefit.

### **7.2.1 REALISING BENEFITS FOR CONSUMERS AND THEIR CARERS**

As this report has suggested, consumers stand to gain a great deal from the successful introduction of the EHR in Australia. To realise this potential benefit, they will need to believe that the EHR has been designed to meet their needs and is working to their advantage. Importantly, their records must be accessible when required for any purpose they deem necessary for their health and wellbeing. These purposes are likely to vary considerably from person to person with older people and the chronically ill wanting more open communication and continuity, and younger people wanting greater privacy and control.

Consumer confidence is essential to establish the EHR and realise its benefits. However, achieving consumer confidence is perhaps the single greatest challenge to the introduction of a national approach to EHRs. There is a necessary balance between maintaining privacy and confidentiality and achieving access when required or deemed necessary by consumers. Consumers have generally had a high level of trust in the way health professionals have protected the privacy of personal health information, but to some extent this is because of the inadequacies of paper records as an information source. The paper record is largely impenetrable to those seeking specific information, especially for untrained users. Moreover, health staff generally only have access to the health records held at a single site.

The EHR is a superior information source. Consequently, consumers will want ‘fine grain’ control over what they keep private. Their confidence will only be established when they can check the contents of their records and be certain who has accessed them and for what reasons. Inevitably breaches of privacy will continue to occur but they will need to be limited to an acceptable rate and must be dealt with severely.

Further, EHRs will be more accurate if consumers have unfettered access to their records - they are the most important ‘brokers’ and can ensure information is complete and not excessive<sup>270</sup>. Data entry by patients has been demonstrated to improve the EHR and needs to be further developed. Consumers will need to be involved in the design and implementation of EHRs to maximise benefit and adaptation to their needs. Studies indicate that they are far more likely to access their records if they are available on line or via touch screen or hand held devices. The expertise and capacity to meet consumer requirements need to be developed and maintained in a form that is likely to continue to serve the interests of consumers.

Consumers may wish to partake in electronic communication with health care professionals and provide access to their EHR as part of this interaction. Accuracy of infor-

mation accessed online from anonymous health care professionals can be highly variable in quality<sup>276</sup> and a framework for certification and security is required to enable such communications to be undertaken in confidence. Guidelines are required no matter how well intentioned the provider may be<sup>277</sup>. Although such communication may seem unnecessary in urban centres, this facility may be highly desirable in rural settings. Direct access by patients to specialists and pharmaceutical companies may have unforeseen implications on costs in the health service and controls should be considered.

In specific situations special provisions may be required to ensure equity. For example, approaches to moral and legal issues are more complex in the area of mental health and need careful consideration. Rigby and colleagues have begun the development of specific guidelines in this area based on the European principles<sup>273</sup>.

There is a very real concern that IT in health care will be used as a means of justifying the withdrawal of health services in rural and remote settings - rather than improving access. The required infrastructure on which to base EHR systems may be more expensive in these settings and may not be made available. Finally, disadvantaged groups are unlikely to have the resources to invest personally in computers and will need access through public services.

Importantly, the most efficient way to positively influence patient outcomes (as well as cost of care) is by proactively influencing clinicians' orders<sup>21</sup>. Consumers, therefore, have a genuine interest in the implementation and evaluation of EHR systems.

Aspects of a national approach required to assure consumer benefit are:
<ul style="list-style-type: none"> <li>The new paradigm demands an explicit legal framework for the EHR including               <ul style="list-style-type: none"> <li>a requirement for each site to publish clear information policies and procedures to ensure appropriate work practices,</li> <li>a national EHR security and privacy framework with uniform legislation, and</li> <li>a national approach to training health professions who access EHRs in the understanding of the duty of confidentiality and the legal sanctions for not observing it.</li> </ul> </li> <li>The needs of consumers and health professionals will have to be reconciled through involvement of consumers in EHR system design so that the aims of both parties can be achieved.</li> <li>Data entry tools for consumers and a consumer 'view' of clinical (coded) information need to be developed and the EHR architecture needs to evolve to support this.</li> <li>A suitable registration and certification scheme needs to be implemented for health professionals who make themselves available on line - controls may be required.</li> <li>Monitoring of EHR services needs to be established in various contexts to ensure equity of access for all consumers.</li> </ul>



### 7.2.2 ENSURING BENEFITS FOR HEALTH CARE PROFESSIONALS

Health professionals are not able to cope with the information overload. Many recent technological advances in medicine add considerably to the amount and types of information collected. In addition to keeping a historical record of care, clinicians are expected at times to provide patients with hand held records, complete complex forms for different bureaucracies and record enough information to prevent unwarranted litigation. Elaborate care plans or medication charts require complete rewriting when the paper form is full, time expired or just worn out. Information is required to be entered many times to fulfil the requirements of recording care, the reason for the investigation, a flow chart to monitor chronic disease and a referral to another clinician. In the setting



of modern health care the manual or paper record has many shortcomings (see Section 7.1.3 on page 98) and the EHR offers a leap in functionality and return for the effort expended in recording patient data.

However, health professionals generally understand current work practices and, although possibly complex and inefficient, the shortcomings are well known. Changes to work practices can be threatening and demand learning and commitment<sup>278</sup>. In addition, health professionals may find data entry slower, more limited<sup>107</sup> and a perceived interference in the clinician-patient interaction and relationship.

There is now sufficient experience to be reasonably sure that introducing the EHR needs to be an ‘organic’ process, led by knowledgeable clinicians<sup>105</sup>, with health care professionals involved in the selection and implementation of the system. Furthermore, systems introduced into hospitals with no real sponsorship by medical staff seem likely to fail<sup>105</sup>.

A further key challenge to a national approach is acceptance by health professionals. After a period of major change in health care, introducing an EHR nationally will demand further adaptation. Health professionals will need to understand the basis for change and, if that change is fundamental, the need for it will have to be quite clearly expressed<sup>81:p7</sup>.

*Doctors think that they have been living through years of uncomfortable change, and they have. But the pace of change is unlikely to slow, and our health care systems will probably see more changes in the next 20 years than in the last 20.*

At present, many of the benefits of the EHR can only be achieved at single locations. From a health professional’s perspective, the task is to enable transfer of the EHR or access to it from another system while preserving the integrity of the information and therefore the ability to process it automatically. This is the holy grail!

*It is in the degree of structure in the data that the exemplary [E]HR projects rise above the others. Structured data are the only means by which data elements can be manipulated. The more granular, or highly structured, the data are, the greater the ability to process data into useful forms.<sup>110</sup>*

Achieving such structured information demands standardisation of some sort across the domain where communication is to take place - ideally a national or even international approach. The standards must include:

- an approach to entry of data from defined vocabulary sets and a national approach to ensuring that these terms can be processed automatically when the EHR moves with the consumer to different points of care;
- a way of identifying medications, therapies and interventions that ensures safe processing for decision support;
- an approach to messaging from system to system that can be incorporated into the EHR in a consistent manner; and
- an approach to the ‘structure’ or ‘architecture’ of the health record which enables transfer of the EHR between systems.

Formulating an approach to terminology is not simple - a whole of health care solution is proving elusive. There are more than 150 niche terminologies in medicine - a situation that is almost certain to continue. But, SNOMED and the UK Clinical terms (Read) are to merge to produce SNOMED-CT which, although proprietary, may prove attractive as a whole of health care solution. The UMLS remains the only effort to pull terminologies together and provide some coherence<sup>142,21</sup>.

Whatever the outcomes, everyone will need to ensure that health professionals benefit or systems will not be used appropriately. Change needs to be evolutionary, transparent and led by clinicians.

**Aspects of a national approach required to benefit health professionals are:**

- Health professionals must accept the EHR systems. To do this they
  - must be involved in and feel committed to the introduction of EHR systems, and
  - should lead the introduction of the system.
- Introducing EHR systems must take place in a transparent and evolutionary framework with best practice guidelines and careful change management.
- EHR systems must support clinical decision making and information access at the point of care through
  - a standard terminology and medication identifiers,
  - standard messaging, and
  - a fast communications network available to the clinician at the point of care.
- EHR systems should support EHR transfer, access to audit tools, and future proofing of EHRs through a standard health record architecture
- Consumer understanding of the need for student health professionals to undertake supervised access to EHRs must be assured

### 7.2.3 BENEFITS FOR MANAGERS

*Measuring the quality of health care delivery is one of the most critical challenges facing US health care. Performance measurement can be used to track the quality of care that health plans and medical groups deliver, but effective performance measurement requires timely access to detailed and accurate data. (Schneider<sup>279</sup>)*

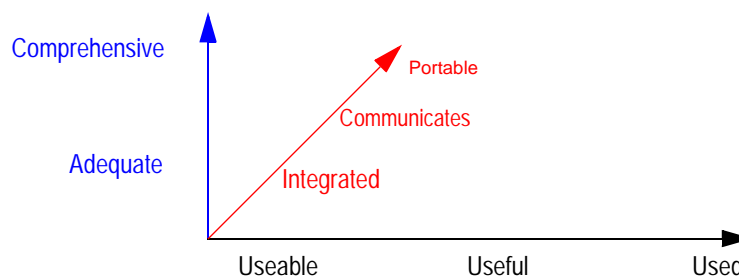
Managers are concerned with efficiencies and quality of health information. The price of implementing systems to monitor these aspects has proved prohibitive with paper based records<sup>279</sup>. For this reason managers have, by and large, anticipated the future introduction of the EHR *but* not necessarily the future health care environment nor the privacy concerns of consumers.

For managers it is important to achieve a step-wise approach from paper to a fully electronic health record<sup>105</sup>. This first step is the ability to accept and send electronic information utilising HL7 messages. Paper documents can begin to be scanned when they are received - particularly with new technologies which support the transformation to text and images in a single step. With improved security techniques patient access must be enabled; first locally and then from other sites. When data entry technologies are adequate, health professionals will use their computers enabling the site to move towards a 'paper free' state. There is a further dimension to this evolution; that of progressing from using the computerised information to support management and aspects of clinical care to the point where the EHR is used as the primary source of information by clinicians (and others) when providing health care to individuals or families.

Finally, the information can be stored in an EHR with a standard architecture which will enable transfer of the record or parts thereof to other sites that utilise the same standard. In the future, the EHR *must* communicate and be portable.

FIGURE 6.

Axes of development of the EHR.



Implementing an EHR system is a complex process that must evolve over time<sup>182</sup>. Mount and others suggest a regional and incremental implementation of the EHR with an 'opt in' approach for consumers. This will then grow geographically while adding further record functions<sup>280</sup>. This approach is favoured in NSW<sup>158</sup>.

The CPRI in the USA has shown a number of features of the most successful EHR system implementations that warrant careful attention<sup>110</sup>. These are summarised in Table 12 below.

**TABLE 12.** Features of the 9 hospital EHR implementations awarded 'Davies' recognition by the CPRI (USA)<sup>110</sup>

Feature	Description
Long term projects	EHR implementation over many years - the quickest was over 4 years (with a product developed over 20 years.) and may continue over many decades "The single most important feature is that it is not finished!"
Involve ambulatory care	The needs of ambulatory (rather than inpatient) care appear easier to meet and developments can then be transferred to inpatient care.
Involve decision support	These systems depend on a significant amount of data to be successful and probably require clinicians to depend on the EHR system as the primary source of information
EHR is not an end in itself	EHR seen as a means to achieve improvements in health care quality, cost and access.
Sustained leadership by skilled clinicians	Commitment at the top to a (shared) vision and to bringing the value of information to health care. Average longevity of health managers is 2.5 years - average tenure in successful EHR sites is 8 years. All had clinicians as leaders

**TABLE 12.** Features of the 9 hospital EHR implementations awarded 'Davies' recognition by the CPRI (USA)<sup>110</sup>

Feature	Description
Management of the health care facility	Poor processes are magnified by conversion to electronic form. "Attention to management factors is probably the most important step in implementing [E]PR systems"
Sustained investment	EHR is seen as an infrastructure issue - not just a capital investment with immediate returns.
Adaptation to local requirements	Not a single EHR system was an off-the-shelf solution - rather home grown or significantly modified commercial product. This suggests the need for high calibre IT staff.
Stable vendors	The development is likely to go on for many years - so a vendor who is likely to be in there for the long haul is required.
Focus on end user	All go well beyond the clinical representation on steering committees, help desks - and "reflect the real influence of users in the continued development of the project". Even in multi-site roll-outs the implementation must be local.
Structured data	More highly structured data means more useful data which can be processed and provide decision support and other functions.
Data integrity	Autoloading data from other devices - biometric, ECG etc. and checks at the time of data entry, tracking compliance with documentation requirements etc.

A national approach makes it *more* likely that implementing EHR systems will lead to cost savings and productivity improvements as the greater the level of electronic exchange, the more commitment to the EHR as the primary data store, the more complete the record, the more reliable the processing and the greater the benefits. Institutions will have a firm basis to proceed with accreditation and other requirements through standardised reporting. Demonstrated cost savings will, however, be required before some institutions will be willing to embark on the process.

Managers want to protect their data for future use. A published standard for EHR information architecture and approach to terminology and classification will assist in the development of an open software market for EHR solutions, ensuring interoperability and preventing the "vendor lock-in" syndrome. HL7, despite its shortcomings, is an example of a published interoperability standard that has enabled interoperability within and between some health institutions. In Australia, fear of vendor lock-in has probably been one of the impediments to centres computerising earlier. Actual vendor lock-in is probably an impediment to the quality and, particularly, the comprehensiveness of clinical information captured in primary care.

With a national EHR program in place, the costs of hospital in-house development of basic EHR systems could be expected to drop. This is because the costs of requirements investigation, information architecture design, terminology standardisation, and interoperability approach are substantially replaced by work carried out and published at the

national level. Some of the actual costs of implementation of EHR applications and systems borne by hospitals would be replaced by externally purchased components and applications, which are known to comply to relevant national standards and architectures. In-house IT departments would be able to concentrate on value-added systems and applications, improving the level of information support at each particular facility. In other words, the "industry average" of information support for health care would rise.

Managers and policy makers are interested in the care of individuals across the system. With electronic data interchange the recognition of an individual is assured as long as the patient identifier is known within each domain. Thus, a request for a pathology test can be accompanied by an identifier generated at that centre and the result returned with the same identifier. With this local approach, all past results ordered for that person from that centre can be identified. An issue arises if the person attends a number of health providers and seeks care for the same problem - a practice that is accepted in Australia. If the health professional at a new site now seeks pathology results taken previously, the local identifier is no longer sufficient for this purpose. The pathology provider, in this scenario, will not be able to safely report all tests for this person without checking identifiers such as name, date of birth and address. Many people in small centres, particularly working in the health care setting, are very uneasy about having identifying data on test requests. The pathology provider does not really need to know this information in the present system (and does not in countries such as Switzerland) as long as billing information is available (i.e. Medicare number). However, it must be stated that with paper records a name is very useful!

A national approach can attempt to overcome this difficulty of providing health information about specific individuals easily and safely by instituting a personal identifying number (PIN). The key advantage of a PIN is the unambiguous recognition of an individual across the health care system. A national PIN has been instituted in the UK although consumers usually attend the same centre for care. It has also been implemented in New Zealand and Canada and is mooted in South Australia and New South Wales. The advantages and disadvantages are summarised in Table 13 below.

**TABLE 13.** Advantages and disadvantages of a personal identifying number in the health system

Advantages	Disadvantages
<ul style="list-style-type: none"> <li>• Unambiguous recognition of an individual across the health care system</li> <li>• Anonymisation of requests for pathology and other care if required</li> <li>• Immediate access to results of previous tests on a particular patient</li> </ul>	<ul style="list-style-type: none"> <li>• Maintenance of the national database</li> <li>• May require patient-only access to national database for resolving from numbers to patient details</li> <li>• Personal health information will need to be 'locked' unless patient consent is registered.</li> <li>• More communication required; systems for temporary generation, automatic messages and later confirmation if the number is not known at the point of care</li> </ul>

In the new health environment with EHRs, managers will be responsible for ensuring security and confidentiality<sup>166</sup>. To do this they will need resources and a clear legal

framework in which to act and deliver sanctions<sup>65</sup>. Security requirements must be explicit, as must provisions for the backing-up of data<sup>281</sup>. A means of authenticating users, such as smart cards, retinal or finger print scanning, must also be provided. It is essential that managers are able to meet these requirements within a framework that does not inhibit use of the system by the health professionals. This is unlikely without adequate sanctions at present as watertight security is too onerous to operate. This may always be the case.

Aspects of a national approach that will meet the needs of managers
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- |  |
|--|
| <ul style="list-style-type: none"> <li>• A legal framework and best practice guidelines need to be established for               <ul style="list-style-type: none"> <li>• security of health data,</li> <li>• managing the introduction the EHR,</li> <li>• the balance of access and security appropriate in different settings,</li> <li>• system performance and useability,</li> <li>• collecting management data as a by-product of recording care.</li> </ul> </li> <li>• The introduction of a personal identification number (PIN) needs to be carefully considered to aid local management.</li> <li>• The vision of the health system of the future needs to have a 'step wise' implementation that is coherent and safe and reasonably inclusive.</li> <li>• Health care professionals and consumers need to be aware that the importance of the EHR will often extend beyond the immediate consultation and for that reason will need to be structured and carefully maintained.</li> <li>• Transparent methods of requesting and recording of consent for use of personal health data for management purposes should be incorporated into the EHR development.</li> <li>• A mechanism to bring about standardisation of EHR systems needs to be instituted, providing added resources for those who fully implement standards, some of which must be passed on to system developers.</li> </ul> |
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#### 7.2.4 COMMERCIAL SOFTWARE VENDORS

*Just tell us what to do and we will do it - but tell us for God's sake - because we have to do it now!"* (Anonymous, software developer).

National approaches can work to the advantage of the commercial health software industry. Developers can use nationally agreed standards and guidelines for core requirements, information models, and interoperability, enabling them to reduce the costs of developing their own versions of this core work. Commercial vendors can also reduce the costs of implementing basic EHR facilities, by sourcing standard components, such as prescribing modules or terminology services, built to national specifications. They will then be able to focus their resources on value-added development, particularly on higher quality GUI applications, specialist systems, and integration with billing and accounting systems.

The large majority of software vendors benefit from the certainty and stability which standards bring, provided these standards are implementable at reasonable cost and have strong support from relevant standards endorsement bodies. The only vendors who resist standards are those with a monopoly market position based on a non-standard, proprietary technology or product. Standards in this situation threaten vendor 'lock-in'. This phenomenon is common around the world at present in the field of clinical software and EHR systems.

*In conventional sectors of industry, standards are well known for increasing companies' market opportunities and for lowering the*

*cost of equipment and services to users. The same arguments hold for the field of healthcare informatics, where European industry currently supplies to a fragmented market, products which have a short life cycle and are over-customised and therefore expensive to develop, to buy, and to maintain. Agreement on common requirements will reduce the cost of healthcare information systems and open up the market. (Directory of the European Standardisation Requirements for Healthcare Informatics and Telematics: Program for the Development of Standards. European Committee for Standardisation, CEN/TC 251, 1996).*

Vendors want realistic application development cycle times - usually about three years. Evidence from the USA<sup>21</sup> suggests that successful systems in use in the future are very likely to be the ones that were leading the way 6 or 7 years ago. This strengthens the argument for evolution or 'growing a record system'.

Aspects required to ensure benefit to software vendors
<ul style="list-style-type: none"> <li>• A balanced approach to the introduction of standards <ul style="list-style-type: none"> <li>• which are easy to implement,</li> <li>• have a limited number of specific implementations (i.e. a generic solution),</li> <li>• are supported by rapid expert decision making,</li> <li>• are internationally compatible where possible, and</li> <li>• are kept up to date.</li> </ul> </li> <li>• A commitment to ensure benefit from the introduction of standards through <ul style="list-style-type: none"> <li>• seeking acceptance by the appropriate industry body that the standard is suitable,</li> <li>• proposing reasonable time lines for implementation of standards, and</li> <li>• ensuring financial reward or at least no financial disincentive for implementing these standards.</li> </ul> </li> </ul>

## 7.2.5 BENEFITS FOR SOCIETY

The EHR is only one aspect of the information age and is evolving as a desirable achievement in a world that is transformed by the new information technologies. So what will future health care systems be like? Andersen Consulting assembled 25 health IT experts in Singapore to consider this question<sup>284</sup> and came up with a range of possible scenarios worth thinking about. These are:

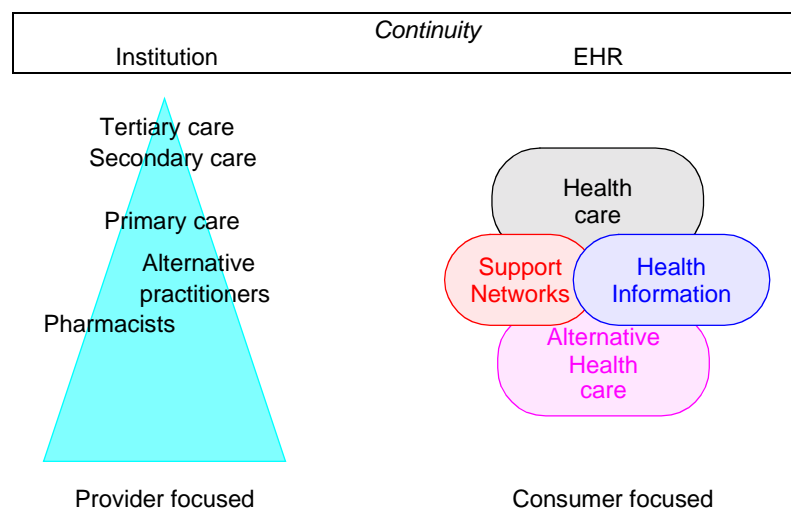
- a socialised health care model with increased incorporation of the tools of managed care - particularly for managing demand (e.g. UK);
- a mandatory managed care system where multiple competing sickness funds are merged to form a "single virtual payer" (e.g. Germany or Japan);
- mandatory personal saving for health care and low government health care spending (e.g. South East Asia);
- multi-tier with private fee for service, pre-paid managed care health organisations and a basic government funded safety net (e.g. USA);
- integrated "virtual system" with a complex system of health providers, suppliers, funders, insurers and consumers working in new sorts of organisational relationships - with government as a regulator rather than a provider; and
- the "informed consumer" scenario with much less contact between the consumer and the health care system - the consumer seeking advice and treatment

from providers outside the traditional health care system much more often than at present.

Within all but the most socialist approaches, new large multinationals have a great interest in the health sector and their involvement will be difficult to check. The recent investment by News Corp in Healthion (the largest new health information business established by the founder of Netscape) is evidence of this move. Microsoft has established health user groups internationally. Will Disney be interested? Consumer guidance to quality information by means of credible (professional and academic) bodies may be the most effective counter-pressure - and a national approach to this is likely to be the most effective.

**FIGURE 7.**

Change from provider to consumer focus



The move from a provider focus to a consumer focus is widely accepted. But in the changing environment, control of the means of continuity, that is the EHR, will be important. The tension will be between these new interests targeting specific groups - individual health professionals, large providers or consumers - or attempting to provide general solutions across all these sectors. All may be seeking to 'lock in' their targets to proprietary solutions - aiming to overcome competition through a large market share. These forces will be difficult to resist and must be taken into account when considering a national approach.

Traditionally academic health centres and hospitals have been in the best position to test and develop EHR systems<sup>285</sup>. Strengthening this aspect of development through research monies and demonstrator sites may be one means of ensuring solutions remain open and in the public interest.

Population data collection is potentially useful to society through research and analysis<sup>137,287</sup>. The costs of interfacing the various health departments' computers with provider systems and processing provider data should drop due to EHR systems and standards. Much of this cost will be saved by the providers, since they are normally responsible for establishing data feeds according to government specifications. Health departments should realise a rise in quality of data extracted, since they can make



assumptions about what information is available, based on provider support for agreed national information models. The potential benefits to society of such uses of EHR systems have been listed by Mount et al.<sup>280</sup>:

- better informed policy development;
- improved resource allocation and management;
- outcomes and cost-benefit analysis of interventions;
- identification of causes and risk factors of disease;
- more efficient collection of demographic data for management and epidemiology purposes;
- monitoring of disease outbreaks and adverse reactions;
- establishment of registers for diseases, devices and treatments; and
- post-marketing evaluation of drugs, devices and procedures.

These functions depend on record linkage, which is greatly simplified by patient identification numbers.

Finally, a national approach will align activities which will have to be repeated around the country. Some activities should be centralised so as to minimise duplication of effort. These core activities should be carried out with adequate resources and the ability to consult widely and rapidly with key stakeholders ensuring that the process is inclusive of special situations such as rural and remote populations, Aboriginal health, migrant health, the elderly and people with disabilities. Examples of such activities are:

- the development and maintenance of a vocabulary required for health care in Australia based on ICD-10-AM, ICPC 2 Plus and CHIME;
- linking this vocabulary to the UMLS to ensure safe mapping and generic decision support tools;
- determining which terms will be used to label data in messages and aggregated data sets, in the first instance, and the health record in future enlarging the national health data dictionary;
- rapidly agreeing message descriptions that will be used in Australian health care and determining methods of easing and encouraging implementation;
- determining the benefits and uses of application interface technologies such as CORBAMed and COM+ to enable 'modular' solutions in the health industry; and

- guiding the development of a standard EHR architecture to enable direct consumer access and maintenance of integrity of the EHR at transfer.,

Maximising the benefit to society
<ul style="list-style-type: none"> <li>• The roles of the EHR are determined within the health model operating in that State or Territory.</li> <li>• Open standards underpinning the EHR which prevent 'lock in' to proprietary solutions and maintain interoperability and communication.</li> <li>• Introduction of a national health person identification number (PINs) to allow record linkage and thus quality information for research and policy development.</li> <li>• Establishing an agency to monitor and advocate for implementation of the EHR, particularly for consumers and health professionals.</li> <li>• Explicit accreditation of EHR systems through a transparent process and undertaken by a body with a consumer focus and mandate.</li> <li>• Nominated national organisations to undertake and advocate for the ongoing development of the 'building blocks' of the EHR and guide its use nationally.</li> </ul>



## 7.2.6 A WORKED EXAMPLE: THE EHR AND ELECTRONIC PRESCRIBING

Achieving benefits is complex and many aspects are specific to one domain of health care. As an example of a detailed analysis of benefit, the implementation of a national drug identifier database is considered in detail - drawing on lessons learned in the United Kingdom.

Implementation of a national drug identifier database, for all therapeutic substances, is a major pre-requisite for prescribing in the context of a national electronic health record. It offers unique identification of a product at the point of prescribing, dispensing and in analysis of either an individual patient record or across patient groups. The wide variety of clinicians who may contribute to the record, would all use a common term or code, no matter what organisation they represented, resulting in consistent electronic data. These data may then provide input to interrogation modules, whatever their purpose, be it viewing a drug history, dispensing, decision support or data analysis.

### *Improved access to prescribing information for providers and consumers*

The drug database should provide a unique identifier for the drug or product that is linked to its name, strength, formulation and pack size. Subsidiary data could then include: generic equivalent, drug action group, cost, product licensing information (indications, dosage, contra-indications, warnings, precautions, side effects, and manufacturer).

Software companies, writing clinical applications, could then use these nationally accepted data and could make them available to a clinician at the point of prescribing. Consumers may use a Web-based application if they wished to make an enquiry and data extracts could be presented in a suitable format.

### *Improved support to providers and safety to consumers*

The Quality in Australian Health Care Study<sup>288</sup> gave two examples of serious, drug treatment related adverse events. The first described the prescribing of a beta-blocker (for hypertension) to a known asthmatic - the patient developed acute respiratory failure; this was an example of prescribing when a contra-indication was present. The second patient developed gastro-intestinal bleeding having been given a non-steroidal anti-inflammatory drug; this was an inappropriate prescription for what turned out to be osteo-arthritis. The former instance had a "preventability score" of 6 (the maximum), the latter a score of 5.5. The national drug database, together with the subsidiary data, could be incorporated into suitability checking software and used to prevent such errors, resulting in an improvement in the safety of the prescribing process.

The suitability checking modules could check that there was an appropriate indication in the EHR for the proposed treatment and that the dosage was appropriate for the patient (based on age, sex, weight and renal function)

With suitable computer-interpretable coding, the EHR could be interrogated for:

- contra-indications;
- illnesses attracting warnings;
- previous adverse drug reactions;
- allergies;
- drug interactions on the same and recent prescriptions;
- drug interactions with "current medication" lists;
- patient therapeutic preferences where recorded;
- checks for duplicate therapy (two treatments for the same condition); and
- drug doubling (where an ingredient is common to two prescribed products).

Such interrogation is a simple matching process and does not require "intelligence" or incorporation of medical knowledge. Alerts could then be presented to the clinician before dangerous or inappropriate prescribing decisions were made. Clinical information systems could then present users with alternative products based on similar actions or indications as appropriate.

***Improved cost-effectiveness of prescribing***

Computerised prescribing systems have the potential to reduce costs and improve cost-effectiveness in three main ways:

- increasing the appropriate use of generic products;
- offering alternatives drugs ranked by cost; and
- presenting drugs ranked by evidence-based effectiveness for the given condition.

Figures published by Oxfordshire Health Authority in the United Kingdom suggest that general practitioners can achieve up to 80% generic prescribing while still maintaining standards of therapeutic care and clarity of prescriptions to dispensing pharmacists.

***Improved Electronic Data Interchange***

A single national identifier for therapeutic substances minimises the change in meaning that may occur in EDI from sender to recipient. This added safety may allow transfer of prescription data directly from clinician to the dispensing pharmacist chosen by the patient.

***Improved "current medication lists"***

Patients may consult with multiple health professionals either by choice, because they require care from both the primary care sector and the secondary care sector, or because they have multiple illnesses. Each clinician may change the drugs that are recommended for the patient and may not even be aware of who to inform that such a change has occurred. The easy transfer of prescribing history in an EHR would allow all clinicians to have an accurate, up-to-date "current medication list" for the patient in front of them.

***Improved access to information***

A unique identifier for therapeutic substances allows specific and rapid information access by the health professional at the time of administering or prescribing therapy. Independent publications available in Australia can be accessed in this way to improve patient care. Patients can also access this information from the same public database via the internet - particularly if their EHR is accessible.

**Improved public health data**

Routinely collected, computerised primary care data has been shown to be useful in infectious disease surveillance<sup>291</sup>.

Analysis of pooled general practice data can also result in new information about other kinds of event: for example the effect of press releases about the dangers of contraception, on pregnancy rates<sup>292</sup> and for pharmaco-vigilance<sup>294</sup>. Finally, the pharmaceutical industries and consumers (and clinicians on their behalf) have an interest in monitoring the adverse effects associated with medications. A national EHR and Drug identifier would enable such monitoring<sup>120</sup> and may lead to the early recognition of adverse effects as well as establishing the safety record of other medications.

### 7.3 POTENTIAL DIFFICULTIES OF INTRODUCING A NATIONAL APPROACH

Notwithstanding the benefits of a national approach, important difficulties must be considered. Not the least of these is the pressure to act in haste. Take for example the 1997 the HIMSS and Hewlett-Packard Leadership Survey to determine the 'futuristic' health care technologies *most likely* to come into common usage during the next 5 years. They are listed in Table 14 below.

**TABLE 14.** Futuristic health information technology most likely to be in common use by 2002. HIMSS/Hewlett-Packard Leadership survey 1997<sup>289</sup>

Technology	Percent
Access to EHRs via the internet	25
Complete patient record kept on smart cards	18
Remote diagnostics for patients at home	18
Increased use of computers in surgical procedures	8
Automated pharmacies and drug disbursement	8
Preventative medicine in the home	8
TeleDoc to and from home	5
Genetic health mapping	5

These developments have not been realised to a large extent. Such over optimistic predictions are the norm in health informatics. A national approach should have clear aims and objectives but needs to resist being stamped into action with unrealistic forecasts.

A further difficulty is the stagnation of development that begins when a national solution to a difficulty is promoted. An example is the Coding Jury to determine which vocabulary will be used for Australian general practice, which has been in limbo for some years. This has led to a great deal of uncertainty amongst software vendors and developers regarding commitment to a coding system. We are now in the position that many have taken up ICPC Plus and a determination by the jury of an alternative would be difficult to enforce.

*Technology dedicated solely to health care applications risk being orphaned due to lack of a mass market. The market drive of consumerism must pave the information infrastructure for health care applications. (Tang<sup>21</sup>)*

The roles of some health professionals are likely to change with the transition to EHRs. The importance of training for clinical users has been stressed but it is equally important for non-clinical staff. Health information managers will have a major change of role and staffing levels of hospital records departments will be reduced. This needs to be accounted for in future plans to prevent problems.

### 7.3.1 REGULATION, SLIPPERY SLOPES AND THE STATE

The need for regulation has been widely justified from all perspectives - but state control is also dangerous. Involving the state in the administration of personal health information may lead to a number of "slippery slopes" - these must be considered. First, the selection of the type of health record environment<sup>290</sup> for the future will impact on the health care system. Second, the argument about public interest can lead to abuse by the state. Third, the excessive use of technology and automation will allow the association of other public functions and impact on privacy.

#### *Health record environment*

There are three general models that are possible for implementation of the EHR. The first is a 'closed' system, an electronic version of the present situation, which does not work if consumers are mobile and seek their care at a number of centres. The second is an 'open system' where collections or centres share an EHR for an individual. This system provides the most threat to privacy. The third option is a 'patient-controlled system' with patient directing access to their records. These models are summarised in Table 15 below.

**TABLE 15.** Three models for EHR approaches

Closed	Open	Patient controlled
Hospital department, Community Health centre, General Practice or similar hold record.	Centralised record storage.	Patient controls the record, may be hand-held or trusted third party.
Maximum control for clinicians.	Maximum access to clinicians.	Maximum privacy and control for patients.
Compromise in patient care and privacy; suitable if continuity is valued.	Maximum threat to confidentiality of patients and clinician.	Maximum threat to patient care as record may not be available.
Moderate technological requirements.	Dependent on development of telemedicine.	Dependent on appropriate storage. Will require backup?

#### • *Closed*

The *closed system* is a model based on the current system and makes present regulation more applicable. The EHR is substantially in the control of health professionals who have a personal relationship with patients. However, the closed system is potentially opaque to consumers with messages moving between systems and no certainty about what information is held where. Consider the situation where a small centre stops co-operating with an individual and is unwilling to release the EHR to other centres. Perhaps the centre may not be able to provide the record on a 24 hour basis, so critical information is not available at a time when a patient is seriously ill and the patient's care may suffer in consequence. Internal security in a small centre may be much less stringent, and theft of computers, for example, may be a real risk.

#### • *Open*

With an *open system*, the state will potentially be able to process records without consent for whatever purposes they would wish on the grounds that anonymity was preserved and the purpose of the processing fell within a category which is considered to be in the public interest. Further, a large record store may be sabotaged or physically

damaged, thus destroying all the data on many thousands of patients. This aggregation of small EHR stores into a large centralised database under state control is the first slippery slope.

*The likelihood that unauthorised use will be made of information is a function of its value and the number of people who have access to it. (Anderson<sup>293</sup>)*

Large centralised databases raise the value of information - more comparisons can be made - and also the number of people who require access. For this reason, one may assume that risks to confidentiality grow in a logarithmic relationship to the centralisation (and size) of the information store.

• *Patient controlled*

In a *patient-controlled system* an individual would control the access to the health record through third party security or by carrying a smart card or similar device with them. They would then enable access to their record at a centre where they sought health care. It is possible to provide the patient with control of access and processing as well as ownership - as is evidenced by large corporations in the USA offering these services. Problems arise when people present without access to their records seeking help for a problem that cannot be dealt with safely without the EHR.

*For the moment, the safest system involves a closed system and a patient-controlled system operating at the same time. The one most persuasive argument for the closed system is that medical records can then evolve in their role as can attendant regulation, with progression toward the open or patient-controlled system if appropriate. None are 'ideal'.<sup>6</sup>*

***The argument for public interest***

Another opportunity for abuse by the state rests with the argument for "public interest" overriding personal privacy. Most professional codes around the world including the European Directive<sup>156</sup> now allow for health professionals to break the confidence of patients for public safety reasons or for state security. This is the second slippery slope - with ever growing reasons to break patient confidentiality.

***Excessive use of technology***

Finally, the means of communication between health care providers is also of concern if unregulated or under state control. Information about individuals can be linked and aggregated to scrutinise or monitor people for various reasons. With increasing use of information technology and data collection under State control, the possibility for abuse expands exponentially. This is the third slippery slope. Concern led to a boycott of The UK's NHS network<sup>240</sup> by the British Medical Association over the threat to privacy. In taking a national approach, we must be acutely aware of the dangers of control by the State.

**7.3.2 THE DUTY TO PROVIDE EDUCATION AND SUPPORT**

The literature strongly supports the need for training and support to be implemented within a national approach to the EHR. In their survey of 300 general practitioners in central Sydney, Bolton and colleagues demonstrated that the greatest need of general practitioners was for training (60.38%), closely followed by being assured of support (59.3%)<sup>206</sup>.

Health professionals and other authorised users remain the greatest risk to patient confidentiality - probably to a greater extent than with paper records<sup>142</sup>. Training in appropriate practice of confidentiality is essential as well as good practice in security and

other necessary practices. Possible educational responsibilities are outlined in Table 16 below.

**TABLE 16.** Education responsibilities for those implementing EHR systems<sup>6</sup>

Who	What aspect	When	By whom
<b>Consumer</b>	Rights as data subject	When a record is created	Data controller
	Right of access	General	Society
	Right to control access	When record created	Data controller
	Right to control movement	General	Society
	Right to control process	When record created When new process	Society
<b>Health professional</b>	Duty to patient	General	Profession & Controller
	Duty to controller	When employed	Controller
	Accountability	General	Profession
	Avoid bad practice	General When new system	Profession & Controller
	Use a system safely	New system Employed	Manager
<b>Controller</b>	Duty to patient	Employed New system	Society or profession
	Duty to clinicians	Employed New system	Society or profession
	Legal responsibilities	Employed New system	Society or profession
	Maintain transparency	Employed New system	Administrator
<b>Admin</b>	Duty to controller	Security policy	Controller
	Duty to users	System installation	Technologists

### 7.3.3 DEALING WITH LEGACY SYSTEMS

A system when implemented immediately becomes a legacy system. Further, any new approach will not be compatible with all legacy systems. Thus, introducing a national approach will ‘island’ some current systems forcing their replacement. The resource implications of a particular national initiative can be quickly gauged through consultation with current system vendors and developers. All centres need to be considered, but any centres that have taken up systems presented as the only choices to receive funding, such as in Aboriginal health services, *must not* be isolated by future developments.

Implementation principles that involve open systems and interoperability must be advocated for and any centres seeking to implement closed systems must be aware of the implications in the future.

**7.3.4 INTEGRITY OF  
THE EHR ON  
TRANSFER**

A national approach to the implementation of EHR systems must not lose sight of the aim for consumers and health professionals to access and transfer EHRs from different host systems. This single requirement has massive implications for the approach taken and any other requirement considered in isolation of this will lead to problems in the future.

This requirement becomes more stringent when the integrity of the EHR must be maintained on transfer. This is not a matter of mapping terminology. Consider the situation in Australia where a hospital sends part of the record to a general practice using the Docle coding system. The system will then map the entries coded in ICD-10-AM to Docle. They will then be added to with Docle codes so when transferred to another GP system using ICPC they will be mapped from Docle to ICPC. If the record then gets back to the hospital, the mapping will be from ICPC to ICD-10-AM. It is unclear what the implications of these mappings may be.

The situation is further complicated when information is transformed to different database structures. It is clear that these sort of mappings and transformations are not safe and for that reason EHRs are not sent from system to system at present.

The GEHR architecture is presently being trialed in Australian general practice to assess its ability to overcome these problems.

**7.3.5 LEGAL  
DIFFICULTIES**

International inconsistencies will remain as is demonstrated by the different value placed on the confidentiality of Pinochet's medical report in the United Kingdom and Spain. Different legal situations are much more problematic within a domain in which consumers move freely, such as Australia. It may lead to reluctance by consumers to provide personal information or a ban on the movement of health records to regions that do not have similar standards.

There are strong arguments for:

- national regulation of EHR developments<sup>286,6</sup>;
- policies and standards for EHR storage<sup>282,283</sup>;
- policy for secure transfer of EHRs<sup>204</sup>;
- policies that “...clearly state the types of information considered confidential, the people authorized to release the information, the procedures that must be followed...and the types of people who are authorised to receive information” under what circumstances<sup>75</sup>;
- health care facilities having authorisation procedures that ensure patients giving consent understand who will have access, for what purpose and over what time period<sup>75</sup>; and
- health care facilities giving patients access to the logs of who has looked at their record.

In the future, consumers may seek automated notification of access to their record.

The legal difficulties of ensuring these regulatory procedures are in place are considerable but should not be avoided. Suggestions have been made that a specific body be established to oversee protection of privacy of health information<sup>153</sup>.

Another legal difficulty is audit trails and assessing whether they are adequate. Audit trails are the technical term for a trace that logs who made what changes to the record



and when. Where should they be stored? How long should they be kept? Are they part of the record or external to it, and should they be transferred with the EHR?

Finally, special groups may require special procedures. Aboriginal communities and other highly identifiable populations may reasonably seek confidentiality for their collective information.

### 7.3.6 WHAT IS A SAFE POLICY FOR ACCESS TO PERSONAL HEALTH INFORMATION?

The problems associated with access to large databases controlled by the state have already been mentioned. Chamberlayne<sup>139</sup> has reported on the British Columbian experience of establishing a Data Access Committee to oversee the access of researchers to data. The committee has classified access requests in the following manner:

- A: no person-specific data is released;
- B: person-specific data is included in the data but all individual identifiers are removed;
- C: person-specific information and identifiers are included but no contact with the individuals will occur and individuals will not be expected to be affected by the research;
- D: person-specific information and identifiers are included and there is the possibility or likelihood that the information will indirectly affect future patient management for those individuals although individuals will not be directly affected; and
- E: person-specific information and identifiers are included and the requester intends to use the information to contact subjects or their families.

Such classifications will no doubt raise concerns about the safety of making such decisions retrospectively through a committee. It is difficult to see what aspects of consent are embodied in these request classifications.

The risk of identification must be established. For example, in a practice of 5000 patients in London the following data items were found to be unique at the following percentages:

**TABLE 17.** Percentage of unique or frequency less than 10 in list of 5000 patients

Data item	Unique	f <10
Date of birth	78%	100%
Date first attended	15%	57%
Postcode	4%	47%

Are these data items anonymous? They are clearly not if associated with other information, and as other lists may be available, clear guidelines on this aspect of anonymisation data are necessary. Birth data and ZIP code uniquely identified one author amongst 315,000 people at a Chicago hospital<sup>295</sup>. Protection of clinicians is also important. A project in the UK<sup>194</sup> to collect retail information at point of sale in pharmacies and sell it to the pharmaceutical industry had to take special precautions to ensure that doctors could not be identified when their prescribing rates dropped off when they were on holiday.

Techniques to de-identify data are available as well as solutions to overcome some of the difficulties for researchers<sup>295</sup>. On the basis of international experience, Anderson<sup>293</sup>

concludes that “*every reasonable non-clinical use of medical records...has been susceptible to a solution using de-identified data*”.

### **7.3.7 TECHNICAL DIFFICULTIES**

The CPRI (USA) has stated that the “current technology does not completely satisfy all requirements”<sup>110</sup>. Data entry technologies are the greatest hurdle. System response time and reliability must also be adequate when implementing an EHR system and may not be possible in a small centre. Also, system security as a technical issue, is still of major concern as is evidenced by the almost weekly publication of different security ‘patches’ for well known operating systems.

Encryption is essential for a successful national approach to EHR implementation, and successful encryption will need to be effected on a national scale. Methods have been investigated in Australia and a draft strategy published by Standards Australia - conforming to both management and technical standards<sup>296</sup>.

### **7.3.8 REQUIRED STANDARDS**

Standards are a complex area and the vision of the EHR in Australia will largely determine the work on standardisation that is required. The ‘federated’ or web-based multi-media EHR would require<sup>235</sup>:

- a shared set of data representation standards such as DICOM, JPEG, HL7<sup>297</sup>;
- a shared set of conceptual representation schemes such as SNOMED-CT or UMLS; and
- a common (retrieved) structure for EHR data across all databases.

A more comprehensive solution that is not technology dependent as recommended by van Bommel in Europe<sup>120</sup> would require:

- an EHR architecture (an emerging focus on conceptual models that build upon, rather than are driven by, the technology);
- a coding system for drugs;
- a syntax for health care data interchange;
- standards for enabling exchange of medical images and related data; and
- user identification.

### **7.3.9 FINANCIAL DIFFICULTIES**

Lock<sup>19</sup> highlights the irony of the UK NHS, “constantly exhorted to strive for greater evidence based cost effectiveness, spending UKP 220 million per year on information technology in hospitals, largely unsupported by evidence of benefit. It seems equally ironic that the output of this incompletely evaluated information technology is often the data on costs, quality, and outcome on which objective appraisal of health services themselves should be based”. This difficulty is widely evident - the tertiary purposes of the EHR, collecting data for managers, planners and others, are successful but do not provide evidence of the benefit of the system itself.

Tang and Hammond<sup>21</sup> believe that cost is still a major barrier. There are three trends which offset these costs in part:

- as technology advances greater performance can be had for the same or reduced price;
- as integrated delivery systems become more common the demand for organised and standardised health data will become greater; and

- governments are increasingly interested in supporting this process.

Specific tasks may be required to develop an EHR framework and may not attract funding. Examples are infrastructure for communications or standards development for messaging or terminology<sup>3:p129</sup> - steps which require coordination, development effort, testing and deployment.

The information which has been collected on the economic implications of the use of the EHR has been collected primarily in the UK and USA, in situations which are of limited relevance to that of Australian clinical practice. The Australian situation is characterised by the mix of stakeholders in the delivery of health care (federal and state government, health insurance companies, medical practitioners and consumers). Each of these parties will have different potential difficulties and benefits as a result of the use of EHRs and will therefore have different attitudes to investment in their introduction and use. The costs and benefits are likely to fall unevenly between the various stakeholders, and may result in barriers to the introduction of what may be from a societal perspective a cost-effective investment.

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## **7.4 EVALUATION**

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*Can we imagine how randomised controlled trials would ensure the quality and safety of modern air travel. (McManus<sup>298</sup>)*

Although such a statement is not directly relevant to EHR systems in health care, it does raise the issue of safety and testing. Many interventions in health care are (ideally) evaluated through randomised controlled trials, but at the time of the evaluation, the interventions have already been deemed acceptably safe by a public agency. Health care information systems may have been tested by the developer from a systems point of view but methods of testing the clinical safety of the system prior to use are not well developed. When they have been attempted<sup>105</sup>, the process may make the product unaffordable! This is in some way analogous to HIV treatments which now cost too much for most people that require them.

Paper records, with their shortcomings in the present environment, are not the standard against which IT solutions, and the EHR in particular, should be measured. Paper records have many disadvantages. The hope for the EHR (and its attendant technologies) is not only meeting and improving this 'paper standard' but also creating completely new ways of working towards improving patient care. The costs of using paper records, paper storage, and paper transfer are also largely unknown.

When evaluating an EHR system it is important to establish whether the system being testing is in fact such a system, what sort of EHR system it is and then how such a system should be evaluated.

### **7.4.1 CRITERIA FOR EHR SYSTEMS**

CPRI has developed three threshold criteria for a EHR system:

1. The EHR system must acquire, store, transmit and retrieve data, information and knowledge from multiple sources;
2. The EHR system must possess information processing tools that provide added value in supporting decisions about patient management;
3. Caregivers must consult the EHR system as their primary source of information for patient care.

On the basis of information in this report and Health Online principles we can add the following:

4. The data subject - the consumer - must be able to access and view information stored in the record, information about who has accessed the record and what purposes the record is used for beyond immediate patient care and when.

#### **7.4.2 EVALUATING EHR SYSTEMS**

There are resources that have been developed for evaluation and testing of EHR systems<sup>210,299,4</sup>. The UK NHS requirements for accreditation (RFA) of general practice systems is a public document and contains test criteria for systems. The CPRI has developed a comprehensive set of evaluation criteria for EHR systems as part of the Davies Recognition Program which may be purchased but is not freely available.

Pure approaches to evaluation of computing systems are probably unrealistic as uptake accelerates and the complexity of systems grows exponentially. Much of medical practice has not been evaluated adequately and our drive to 'improve' remains as unsatisfied and non-reflective as ever. Heathfield<sup>210</sup> makes the following statement about the use of randomised controlled trials in the evaluation of information technology in health care.

*Evaluations by means of randomised controlled trials have not yet provided any major indication of improved patient outcomes or cost effectiveness, are difficult to generalise, and do not provide the scope or detail necessary to inform decision making. Heathfield.*

There are multiple axes of evaluation that might be considered in relation to the EHR<sup>300</sup> such as legal, organisational, financial, business, and health outcomes. The outcomes may include improved diagnosis, more appropriate or effective treatment, fewer complications, greater protection through preventative programs, more decisions that adhere to evidence, less inconvenience.

In order to aid evaluation efforts, projects need to have clear and specific care related objectives stated at start of implementation. It is then possible to assess performance against these.

*Where specific productivity or cost effectiveness gains are sought through the use of information technology in hospitals, these can generally be assessed with health economic techniques. When clinical benefits are monitored, techniques such as randomised controlled trials can be considered, but these are inappropriate for assessing most information technology systems and there are difficulties in quantifying improvements and associating them directly with the use of the information technology system. New methods combining economic and clinical evaluation are starting to emerge and should inform development of methods for assessing information technology systems<sup>19</sup>.*

A list of key resources for evaluation of EHR systems is can be found in the Appendix - Section 9.4 on page 127.

## Part 8 Conclusion



*In essentials unity, in non-essentials liberty, in all things charity.*

*Obtaining a critical mass of [clinical] information online is essential to achieve the maximum benefits from an integrated patient record system. (Dayhoff<sup>301</sup>)*

The benefits of a national approach to the EHR can be summarised as maintaining consumer trust, maximising the efficiency of combined effort and enabling the transfer of information. With concerted national endeavour involving consumers, health professionals, managers and the software industry, Australia is well placed to take part in international efforts to achieve a truly beneficial EHR and, at times, lead this venture. However, it is a long road. The current “system” in Australia is mostly paper-based with a patchwork of incompatible electronic functions. If this development is strategic, sensitively involves the stakeholders and is facilitated by national guidelines, it is likely that costs and risks will be minimised and a much earlier achievement of genuine benefits will result.

To ensure efficient and aligned effort it is necessary to decide what to achieve collectively and how - *in the essentials unity*. These are largely the activities that are already the focus of international groups and include:

- data types;
- vocabularies and Thesauri;
- natural language processing;
- data dictionaries and information models;
- messaging;
- application communications;
- electronic health record architectures; and
- clinical system architectures.

This work on the essentials will have to be adequately funded and provide solutions, even interim solutions, quickly and with authority. The software industry needs to be closely involved in this process - a process which must add to rather than detract from their commercial development. There must be a fair exposure to risk in this endeavour - such that activities that are of benefit to society rather than the health professional, the consumer or software provider should be funded with public money.

Having agreed what the common components will be, a national approach needs to provide no other constraints on the imagination of systems developers to provide what consumers, health professionals, and managers want and need - *in non-essentials liberty*. There is ample opportunity for commercial activity and profit around the implementation of the EHR - installation, adaptation, clinical applications, message incorporation, and third party tools for audit and quality assessment.

To ensure that we get there together, all parties will need to be generous and not let the heady corporate environment of the current 'gold rush' in the information technology industries get in the way - *in all things charity*. The best EHR will be produced through cooperation of all parties, collective commitment to the approaches that show the most promise, and open non-proprietary solutions.

Some things seem reasonably certain. A national approach in Australia will do best if it takes an evolutionary approach, particularly in hospitals. Experience from other settings demonstrates that the best hospital systems are complex and require considerable in-house adaptation or development to be acceptable to users. The centres that are doing well now are the most likely to be doing well in a decade and human factors are the most important element in EHR development. Different institutions and vendors will take different approaches at times - they need to feel reasonably secure in the decisions they take and not be stranded by centralised decisions. If sufficient numbers are isolated then they will largely ignore these central decisions.

'Healthy' software development cycles are about three years in length and fundamental changes in requirements set nationally need to take account of this. A national approach needs to be heralded over a period of time that lets developers take account of it in their normal evolution. Rightly, they will be responsive to their users needs - so it will help if the national initiatives are expressed through users rather than centrally. This can be in the form of requirements for accreditation, as in the UK, with certain funding being dependent on following this national approach. The software industry should ideally be a major player in determining these requirements and the accreditation process.

Finally, it must be acknowledged that some key commentators may not yet be willing to decide on how to move forward and may call for more research or training<sup>213</sup>. They must be listened to in proportion to their knowledge and experience and their uncertainties addressed in the national approach.

A part of any national approach must be the education of the stakeholders - consumers, health professionals, managers and policy makers - in the important issues and difficulties that need to be addressed. To do otherwise will leave a naive public and profession beholden to those with the resources to propose solutions - large multinational corporations and the State. An editorial by Classen<sup>276</sup> in JAMA about clinical decision support states:

*This should be a clarion call to medical schools to develop active research and training in medical informatics and to professional societies to get deeply involved in the process of development, implementation and evaluation of this potent new medical software.*

*We need to understand what constitutes and fosters wellness. We need to know what gives real benefits and desirable outcomes. We can look to technology for tools that may help us do all these things, but we cannot look to technology for direction. The only way we can succeed is to define our values with precision and to make those values drive our decisions and our strategies.*  
(Ball<sup>289</sup>)

The EHR is not an end in itself, rather a means to improve the quality and cost-effectiveness of health care offered to Australians in a secure environment. The data col-

lected should enable health professionals, managers and consumers to be reasonably sure that these outcomes are being achieved. Just so, the Australian approach to the EHR should take into account that it will (to some considerable extent) shape the health care system of the future. The role of government in this enterprise is open to debate, but should avoid the extreme pitfalls of lack of regulation on one hand and ownership of personal health information on the other.

The ScopeEPR project<sup>4</sup> from the UK raises issues that must be taken into account when initiating a national approach. These are:

- Learning from wider experience;
- Avoiding unnecessary reinvention;
- Enabling communication and integration - only possible with a national approach;
- Accessing and investing in shared knowledge resources - via the internet;
- Working with global markets - there are opportunities for Australia;
- Put effort into solutions that may be shared; and
- Monitoring international legislation - being compatible will benefit patients.

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## **8.1 INITIATIVES OF IMPORTANCE TO AUSTRALIAN EHR DEVELOPMENTS**

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There are a number of initiatives around the world that warrant close attention in formulating this national approach.

### ***Standardised terminology and data dictionary***

- The WHO ICD-10-AM - the Australian standard for hospital coding.
- The WONCA ICPC-2 and Australia's ICPC-2-Plus for Australian general practice.
- The American College of Pathologists' SNOMED-CT, the merging of USA's SNOMED and UK's NHS Clinical Terms - (formerly the Read Codes).
- The US National Library of Medicine's UMLS - registering all vocabularies in a common thesaurus.
- The Australian National Health Data Dictionary may be extended to include primary care items through the current General Practice information modelling project that is under way.

Only SNOMED-CT offers a reasonable range of clinical terms for use across all levels of medical care. UMLS provides a way of linking more succinct vocabularies for specific purposes. GALEN may offer natural language processing in the future but, as with voice recognition, remains largely in experimental use at present<sup>142</sup>.

### ***Standardised messages and communication***

- HL7 messaging is the nominated standard in Australia - including the LOINC terms for labelling data.
- PIT is the Australian default standard that is widely used for pathology messages and more recently for radiology - due to its ease of use - but has major limitations.
- UN EDIFACT is the standard for financial messages in Australia.
- The Open Management Group's (OMG) CORBA-Med specification for communication between applications.

***Standardised  
record  
architecture***

- The World Wide Web Consortium (W3C) is developing specifications that are likely to see their eXtensible Mark-up Language (XML) alter the approach to standards, particularly for simple messages.
- The Good Electronic Health Record (GEHR) currently being trialed in Australian general practice.
- HL7 Patient Record Architecture - an XML document structure for messages and patient records.
- CEN, the European Standard's body health record architecture for communication - a development of the original GEHR specification aimed at federating legacy health information systems.

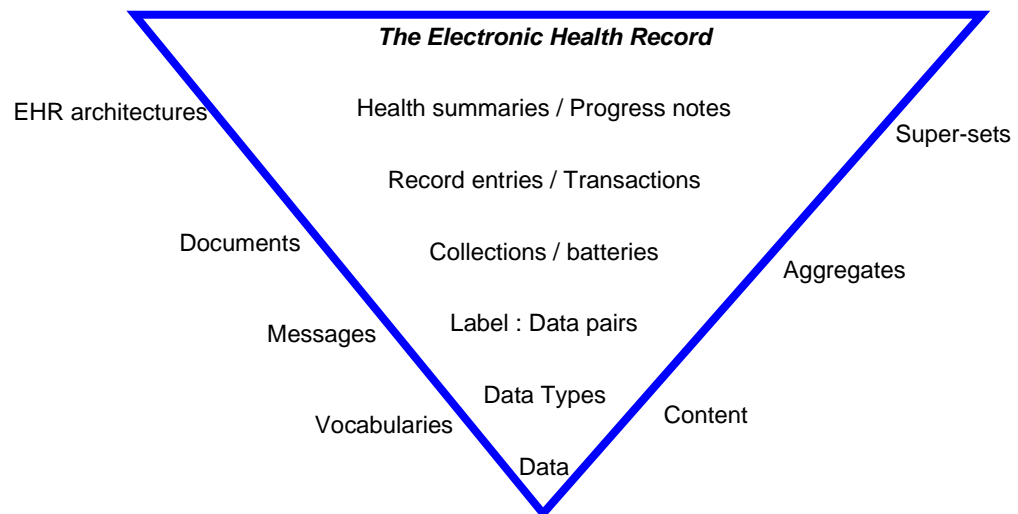
The International Standards Organisation has a number of committees that debate and ratify potential standards for use in health informatics.

Finally, all these initiatives co-exist and interact at some point. Choices made at one level will impact on choices made another level. Evolving work in decision support and pharmaceutical databases will also be critical to the success of an Australian EHR development.

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**FIGURE 8.**

Organisation of health data



Good luck!



## Part 9 Appendix



This appendix contains further information on key texts, European projects impacting on EHR developments, and useful documents from Canada Health. Some key resources for evaluation of EHR systems are listed.

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### 9.1 KEY TEXTS ON THE EHR

Murphy, G., Hanken, A. M., and Waters, K. A. *Electronic health records: changing the vision*. W.B. Sanders Company, Philadelphia, 1999. ISBN:0-7216-7386-4.

Dick, R. S., Steen, E. B., and Detmer, D. E. *The computer-based patient record: an essential technology for health care*. National Academy Press, Washington, USA, 1997. ISBN:0-309-05532-6.

Sampford K. *Access to Medical Records*. Research Bulletin No6/99. 1999. Brisbane, Queensland Parliamentary Library.

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### 9.2 UK INVOLVEMENT IN EUROPEAN PROJECTS

In addition to the core projects of the NHS, a number of UK healthcare, academic and industrial organisations have led or participated in EU funded R&D projects in this field. The Health Telematics Research and Development programme of the European Union has recognised many of the health informatics challenges in the development of EHCR systems and sought to address them on a large scale through a set of multi-national projects over the past decade<sup>302,303</sup>. The main projects on electronic healthcare records have been the Good European Health Record and Synapses projects.

The very extensive investigations of user and enterprise requirements that have taken place over several years have sought to capture the diversity and specialisation across primary, secondary and tertiary care, between professions and across countries. These requirements have been distilled and analysed by expert groups across Europe in order to identify the basic information that must be accommodated within an EHCR architecture to:

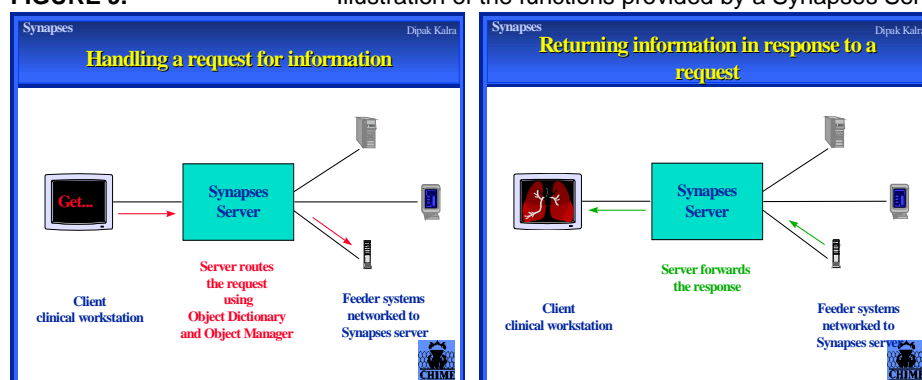
- capture faithfully the original meaning intended by the author of a record entry or set of entries;
- provide a framework appropriate to the needs of professionals and enterprises to analyse and interpret EHRs on an individual or population basis; and
- incorporate the necessary medico-legal constructs to support the safe and relevant communication of EHR entries between professionals working on different sites.

The most detailed review of this domain has been published by the GEHR project<sup>6,9,304,305</sup> and this set of requirements has informed the subsequent work of CEN

PrENV 12265<sup>306</sup> and the Synapses project<sup>255</sup>. The work on EHR requirements is now being taken forward through a new Work Item within ISO/TC 215.

GEHR has published the requirements and information models that should underpin a comprehensive sharable EHR. Synapses has tackled the problems of sharing data between autonomous information systems through the development of middleware servers. Synapses utilises the methodology of database federation to a standard and comprehensive schema (the federation healthcare record architecture), mediated and managed through a set of middleware services. The emphasis of Synapses has been to facilitate data sharing between a set of federated clinical systems via the Server. The Synapses specifications are in the public domain, and have fed directly into recent CEN EHR standards.

**FIGURE 9.** Illustration of the functions provided by a Synapses Server



The preservation of clinical meaning within the EHR also hinges on use of shared or compatible terminologies for capturing clinical statements. The EU GALEN project has pioneered work in the formal representation of clinical concept models, and their cross-mapping to classification systems such as ICD and Read<sup>191</sup>. Further work is being undertaken in the UK, under the auspices of the NHS, to explore the extent to which clinical meaning and other kinds of context<sup>307</sup> can be represented reliably through record headings<sup>308</sup>. New collaborative work with the SNOMED organisation in the US will yield a new terminology for the NHS in a couple of years.

Electronic healthcare communications must take place within an appropriate professional and technical security framework. The EU Projects SEISMED<sup>309</sup> and ISHTAR (<http://ted.see.plym.ac.uk/ishtar/>) have investigated the clinical and legislative requirements and the available products across Europe. This work has informed drafting of the EU Data Protection Directive<sup>156</sup> and related national legislation on patient-related data.

Newer EU projects, such as SynEx<sup>310</sup> and Prompt<sup>311</sup> are developing methods for integrating clinical protocols and medical knowledge environments with patient records systems.

### 9.3 CANADIAN DOCUMENTS

Only Health Canada and the Canadian Institute for Health Information have a national mandate with respect to healthcare informatics. Literature from Ontario is also included as it reflects the most current thinking for EHRs in Primary Care settings.

- Health Canada**      An Agenda for the Future: A National Electronic Health Records System, Endure Siman, Health Canada  
[http://www.hc-sc.gc.ca/ohih-bis/available/coach4\\_e.pdf](http://www.hc-sc.gc.ca/ohih-bis/available/coach4_e.pdf)
- Advisory Council on Health Infostructure Final Report "Canada Health Infoway: Paths to Better Health"  
[http://www.hc-sc.gc.ca/ohih-bis/available/index\\_e.html](http://www.hc-sc.gc.ca/ohih-bis/available/index_e.html)
- Additional documents that are available via the Internet can be found at:  
[http://www.hc-sc.gc.ca/ohih-bis/available/documents\\_e.html](http://www.hc-sc.gc.ca/ohih-bis/available/documents_e.html)
- Canadian Institute for Health Information**      Health Information Needs in Canada, 1998 Canadian Institute for Health Information, Statistics Canada, Health Canada CIHI  
<http://www.cihi.ca/wedo/infonds.htm>
- Health Information Roadmap: Beginning the Journey  
<http://www.cihi.ca/pdf/eng-beg.pdf>
- Health Information Roadmap: Responding to Needs  
<http://www.cihi.ca/pdf/eng-resp.pdf>
- Ontario Medical Association**      Primary Care Reform, A Strategy for Stability  
<http://www.oma.org/phealth/pcare/pcare.htm>
- Ontario Ministry of Health and Long Term Care**      Minimum Functional Requirements for a Clinical Management System  
<http://www.gov.on.ca/MOH/english/pub/pricare/cms/cms.html>

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## **9.4 KEY RESOURCES FOR EVALUATION OF EHR SYSTEMS**

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